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ABSTRACT

Three issues of this newsletter on deaf-blind issues include announcements, reviews, news items, and the following articles: "'What's My Role?' A Comparison of the Responsibilities of Interpreters, Interveners, and Support Service Providers" (Susanne Morgan); "A Support Service Provider Program in Utah" (Cordie Weed); "Valued Outcomes for Students Who Are Deaf-Blind and Their Families: Results of a Survey of State Deaf-Blind Projects" (Lori Goetz and others); "Helping Children Cope with Grief: A Discussion of Options for Parents of Deaf-Blind Children" (Nancy O'Donnell); "The Helen Keller International Art Show: An Annual Event" (Gail Leslie); "It's Never Too Early: Collaborating with State Early Childhood Programs" (Kathleen Stremel and others); "Update on the IDEA Reauthorization Process" (Joe McNulty); "Strategies for Postsecondary Educational and Support Service Personnel Serving College Students with Usher Syndrome" (Patricia Lago-Avery); "It Sounds Nice but Is Inclusion Really Worth It?" (Nancy Hartshorne); "Registry of Interpreters for the Deaf: Deaf-Blind Special Interest Group" (Susanne Morgan); "Grade One Braille for Students Who Are Deafblind" (Linda Mamer); "Assessment as a Creative Action" (Georgia Hambrecht and Karen Goehl); "AADB Mentoring Pilot Project" (Ashley Benton and Jamie McNamara); "National Curriculum for Deaf-Blind Persons and Interpreters" (Mark Myers); "Birth of the World Federation of the Deafblind" (Jeffrey Bohrman and Jamie McNamara); "Meeting Helen Keller... A Miscellany of First Encounters" (Dana Cook). (DB)

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Deaf-Blind Perspectives, 2001-2002

Peggy Malloy, Editor

Western Oregon Univ., Monmouth. Teaching Research Div.

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Deaf-Blind Perspectives

Volume 9, Issue 1 Fall 2001

"What's My Role?" A Comparison of the Responsibilities of Interpreters, Interveners, and Support Service Providers

Susanne Morgan, M.A., C.I., C.T.

Individuals who are deaf-blind access the world differently from their hearing-sighted peers. To ensure meaningful linkages to the environment and equal access to information, a variety of trained personnel and support persons are required. In recent years much attention has been given to the different roles that individuals play in providing this support.

The most familiar type of support is that provided by sign language interpreters. Formal interpreting services were established to meet the needs of deaf individuals. In recent years, these services have been expanded for persons with combined hearing and vision loss. This type of support, however, does not meet all of the unique communication needs of deaf-blind individuals.

Normal everyday life takes place in a variety of settings, including home, school, work, and recreation. For individuals who are deaf-blind, different settings require different types of communication supports. As the developmental, educational, and social needs of deaf-blind children and adults in these settings are better understood, the roles and responsibilities of support professionals evolve. Terms used to describe these roles, include interpreter, intervener, and support service provider (SSP). The following chart attempts to capture the current understanding of these roles and responsibilities.

Interpreter	Intervener	Support Service Provider
Someone who	**Someone who**	**Someone who**
Translates information from one mode or language to another (spoken language to sign language and vice versa)	Intercedes between a child and the environment, allowing access to information usually gained through vision and hearing	Provides support that enhances independence (e.g., facilitating communication, providing sighted guidance, and transportation to/from events)
Works with deaf-blind people of all ages	Primarily works with children and young adults	Provides services to deaf-blind youth and adults who are able to make independent decisions
Is a conduit through which information flows	Facilitates learning and the development of skills (e.g., receptive and expressive communication, interactive behavior)	Facilitates interaction between a deaf-blind person and the environment

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Interpreter	Intervener	Support Service Provider
Someone who	**Someone who**	**Someone who**
May have received professional training in an interpreter-training program	May or may not have received specific training (however, training or coursework is recommended)	Is encouraged to receive basic training in the area of deaf-blindness, including communication strategies, sighted-guide techniques, and cultural issues
Should hold national and/or state certification/licensure and may have a college degree	Has varying educational and vocational experiences (some states offer coursework/certification)	Has varying educational and vocational experiences
Abides by a code of ethics	Acts in a manner that is governed by the local education agency and federal education laws Uses the Individual Education Program as a roadmap for learning Is considered a paraprofessional and works with, but does not replace, the teacher	Abides by standards established by the coordinating agency
Belongs to a national/regional organization of certified interpreters (e.g., Registry of Interpreters for the Deaf, National Association of the Deaf)	May or may not be in contact with other paraprofessionals	May belong to the coordinating agency's network of SSPs May interact with other SSPs during local or national events
Will work in various environments (e.g., educational, medical, religious, social)	Works mainly in an educational setting but may also provide assistance in the community (e.g., daily living skills, medical situations, vocational environments)	Provides assistance in various settings, including the home and community
May be paid independently, through an agency or by an employer Is paid commensurate with certification & local standardized fees	Is paid by the local education agency or a community provider	Is usually a volunteer, unless funds have been allocated
Is required to independently maintain certification through professional development	Is expected to attend workshops offered in educational settings	Is usually not required to attend further training but is encouraged to improve communication skills and interact with the deaf-blind community
Must remain impartial at all times	Wears "different hats" (e.g., as interpreter, guide, facilitator)	Remains impartial but has more flexibility than an interpreter
Must keep all information confidential	Is allowed and expected to share pertinent information with team members (e.g., parents, teachers, related service providers)	Is expected to keep information confidential
Is expected to keep a "professional" distance	Maintains an educational (teacher-student type) relationship	Is expected to act in a "professional" manner, but may develop personal relationships
Acts as a conduit (does not "teach" and is not responsible for ensuring that the deaf-blind individual learns what is being shared)	Is accountable for decision-making to enhance learning	Does not teach but does provide access to the environment to empower the deaf-blind person
Always keeps opinions to him/herself	Empowers individual to make his/her own decisions	May provide feedback/opinions when asked

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A Support Service Provider Program in Utah

Cordie Weed

There are not very many deaf-blind people in Utah. Compared to the number of people who have other disabilities, we are a small group, consisting of 150 adults. Services for adults who are deaf-blind are limited. Statewide, there is only one deaf-blind specialist and one part-time rehabilitation counselor. There are also interpreters, funded by the state legislature, for deaf-blind people who receive training at the Division of Services for the Blind and Visually Impaired or who wish to attend functions there or at the Division of Services for the Deaf or Hard of Hearing. These services are very appreciated, but they barely scrape the surface of the unmet needs of deaf-blind people in Utah.

Recently, however, a new service became available. Beginning July 1, 2001, the state legislature funded a support service provider program. For two years, two of my blind friends and I went to the state capital in Salt Lake City. As members of the Legislative Coalition for People with Disabilities, we asked the legislature to fund a support service provider (SSP) program for deaf-blind adults. We spent many hours talking to the legislators. We also contacted them by phone and mail and inspired others to call and write letters. We let them know that we wanted to be more independent and to live in our own homes. We asked for funding for the SSP program, and we got it.

For many deaf-blind people, life can be pretty empty and lonely. For example, one man who was born deaf-blind and who is in a nursing home has no way to communicate with the staff there. They do not know sign language or how to speak to him. There is no way for him to get involved in activities. He just sits in a chair all day with absolutely nothing to do.

There is also a woman whose family wants to put her in a nursing home because they do not want to care for her. They feel that they cannot cope with her needs. Instead, she chose to move into a housing complex for people who are disabled or have low incomes. This woman is unable to do her own shopping or care for her personal business. She cannot drive herself anywhere. She needs help to be able to live independently.

I know a man who was born deaf and spent most of his years in the deaf community. As he got older, he lost his sight and was unable to continue working. He is now totally blind. Recently, he and his deaf wife went to a social activity at the Deaf Center. He sat there and was bored because he could not see the sign language being used and no one thought to sign in his hands. When he and his wife left, he asked his wife if she had seen the man who had been his dearest friend for many years. She told him that he had been sitting next to him all evening. His friend had not said one word to him and the man was heartbroken.

Some deaf-blind people live in their own homes and are married and have children. Even though their families take care of them, they would still like to have someone take them out for social activities away from the family, to give them a change and to give the family a rest.

I am considered deaf-blind myself. I live in my own home and have a husband and two children. My daughter is married and has a baby. My son is grown but still lives at home. Both of my children grew up coping with my disabilities. I have Usher Syndrome. I am severely hard of hearing and have very little remaining vision.

Even though my family has lived with my increasing disability, they grow impatient and frustrated when I cannot hear or see something. I do not always hear exactly what they are saying, so communication is difficult and misunderstandings frequently occur. My husband has been forced to take on more responsibilities because I cannot shop by myself or travel alone on public transportation. These problems will only increase as my condition worsens.

I love to hear what is being said. I love to be a part of it all, but I am not because I cannot hear or see. I am left out a lot, and it is very lonely. Whenever I get frustrated, I cannot walk out or go somewhere to work it off. I have to stay put until it builds to the point where I explode. Sometimes I feel like I am in a box where I cannot move or let out my frustrations. I was raised to be independent and to take care of a family as well as myself. I want to continue to do that.

I would like the SSP to help me become more independent—to help me shop and walk my dog (a purebred beagle), to read my mail and other correspondence to me, to be my eyes and ears at social activities, and to take me to my appointments. This would also help by taking some pressure off of my family members. It means so much to me to be able to do more for myself. It makes me feel more like a human being.

We deaf-blind people need service providers. We need help with daily living in order to be independent. It is so much cheaper to have a support service provider than to be put in a nursing home. A support service provider can be a friend to a deaf-blind

person and can make the person's life brighter. SSP's assistance can also make it easier for family members by helping to relieve frustration and stress.

I really hope this program will work well for me, for others who are deaf-blind, and for the children who will soon become adults. I hope we will have this program for many years and that it will be successful. I want to make it work and help deaf-blind adults be independent and live happily. I feel very strongly about this program.

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Valued Outcomes for Students Who Are Deaf-Blind and Their Families: Results of a Survey of State Deaf-Blind Projects

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Are schools effectively meeting the educational needs of their special education students? Answers to this question can be provided from a variety of perspectives. A federal law, the Government Performance and Results Act of 1993 (GPRA) [Pubic Law No. 103-62], requires federal agencies to improve program effectiveness and public accountability by focusing on results, service quality, and customer satisfaction. It requires the establishment of measurable goals that can be reported as part of the federal budgetary process. In response to GPRA, the U.S. Department of Education's Office of Special Education Programs (OSEP) developed guidelines for special education programs that list objectives and performance indicators for these objectives (Office of Special Education Programs, 1999).

The uniqueness of the abilities and needs of deaf-blind children poses challenges for the creation of outcomes and tools that measure those outcomes. To determine ways in which the OSEP guidelines could be made more meaningful and reflective of the specific educational needs and goals of deaf-blind children, we developed a questionnaire for state deaf-blind project personnel. It asked respondents what they considered to be valued outcomes for deaf-blind students, their families, and state and local systems that provide services. We defined a valued outcome as a result of the schooling process that is both individualized and perceived as positive and desirable. The development of social interaction skills in greeting peers or advocacy skills in promoting inclusive schooling to a PTA group are examples. The questionnaire also asked respondents to identify tools and strategies used to measure these outcomes.

Results of the Questionnaire

In 1998, the questionnaire was sent to the fifty existing state deaf-blind projects across the country. These projects are federally funded training and technical assistance entities serving schools, agencies, and families of deaf-blind children and youth. Project staff members were in a position to identify outcomes that address the different perspectives of groups and individuals involved in the lives of children and youth who are deaf-blind. Twenty-nine of the fifty questionnaires were returned, a response rate of 58 percent.

The questions were brief and open-ended and did not require respondents to use a specific format. Answers ranged from single words, phrases, and numbered lists to sentences and paragraphs. Given this diversity in format, the answers were analyzed by two independent raters and summarized in categories of valued outcomes (see table). The categories enabled a succinct synthesis that highlighted major focus areas for students, families, and systems.

The raters developed ten categories of valued outcomes for students, eight for families, and five for system-level entities. In addition to identifying specific valued outcomes, several state projects noted that, ideally, valued outcomes for students and families should be developed on an individual basis. Others commented that valued outcomes for deaf-blind children and their families are no different from those for children without disabilities.

In each of the three focus areas (student, family, system), certain responses were mentioned repeatedly by several respondents. Although the number of responses in each category is but one indicator of importance, it is an indication of the valued outcomes that are in the forefront of the respondents' consciousness. The ideas expressed most often in each category are discussed further in this section.

Growing concern with the value and meaning of available interventions and services is reflected in all of the responses. Meaningful participation of the deaf-blind individual at home, school, and in the community is a recurring theme.

Student Outcomes. "Communication skills" and "social skills and friendships" were mentioned repeatedly as valued goals for students. Several respondents stressed the importance of communication skills that are functional and work across different environments (e.g., both at home and at school). Some respondents stressed the importance of the quality of relationships. They noted that there is a difference between relationships with paid staff and those that occur with friends and family, and they emphasized the need to ensure that relationships are mutual and long lasting.

Effective communication and good social skills are important elements for success in school environments. The stress on functional communication and meaningful friendships reflects the outcomes-based planning emphasized in the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA). There has been considerable progress in the development and refinement of interventions designed to improve the social interaction and communication of students with disabilities in regular education settings (Hunt, Farron-Davis, Wrenn, Hirose-Hatae, & Goetz, 1997; Odom, McConnell, & McEvoy, 1992; Strain & Kohler, 1995).

Family Outcomes. The availability of family-specific training was the most frequently mentioned outcome category for families. Respondents identified a need for training in the following areas:

- specific skills to support the child's development, such as adapting environments and materials and learning communication skills and techniques;
- awareness of available resources;
- advocacy skills.

System Outcomes. System outcomes describe results that affect the structures and activities of organizations rather than individuals. Responses emphasizing collaborative planning for organizations were the most commonly identified valued outcomes. The involvement of parents and children in a collaborative planning process fosters smooth transitions and the achievement of independence for students. Parental involvement in educational program and transition planning has also been found to positively affect students' academic outcomes (Morningstar, Turnbull, & Turnbull, 1995-1996; Everson & Moon, 1987; Sales, Metzler, Everson, & Moon, 1991).

Infrequently Reported Responses. Equally interesting and worthy of further research are the categories that received the least attention from respondents. Only a small number of respondents mentioned academic skills and self-advocacy as valued outcomes for students. Only a few mentioned empowerment as an important outcome for families or for inclusion as a system-level outcome. Empowerment and inclusion have received a great deal of attention in the general literature on special education (Dunst, Trivette, & Deal, 1994; Falvey, 1995). It is surprising that they received such scant attention here.

Categories of Valued Outcomes

Student Outcomes	Number of Responses
Social skills and friendship	25
Inclusion into community	16
Communication skills	16
Self-help and independent living skills	15
Work/Career	14
Health, vision, and hearing	12
Recreation and leisure	8
Transition	6
Academic skills	5
Self-advocacy	4
Total Student Responses	**121**

Family Outcomes	Number of Responses
Family-specific training	20
Valued member of family and community	15
Resources for adult independence	14
Resources for families	12
Family stability	8
Connections for families	8
Family/professional collaboration	6
Empowerment of families	3
Total Family Responses	**86**

System Outcomes	Number of Responses
Collaborative planning	30
Staff availability and training	18
Resources for community inclusion	17
IEP/IFSP quality	13
Range of educational placement options	10
Inclusion	5
Total System Outcomes	**93**

Assessment Issues

The IDEA Amendments of 1997 place great emphasis on measuring results through improved accountability and data collection efforts. There is a renewed reliance on the use of assessments to measure the performance of students and their progress toward meeting identified standards. In responses to our questionnaire, we identified a total of eighteen assessment tools and measures, including several curricula and informal methods of data collection such as case studies and interviews. No tool was mentioned with sufficient frequency to be representative of the responses.

Conclusion

The OSEP guidelines describe objectives in general terms such as "improve educational results for children with disabilities." The results of the questionnaire reported here reflect how state deaf-blind project personnel interpreted these objectives in terms of actual practice with students, families, and service providers. For example, development of communication skills and social skills and friendship emerged as key elements for the objective of improving educational results.

There are a couple of limitations to the results of this study. First, the 58 percent response rate limits the generality of the findings. A further limitation is that the questions asked were very brief. A more detailed survey or the use of focus groups would add to the depth of the information that could be obtained.

The development of valued outcomes for students, families, and systems can have direct implications for the evaluation of programs serving students who are deaf-blind and their families. Programs, services, and technical assistance efforts that are consistent with the valued outcomes reported here will strengthen the alignment between actual practice and the goals of those who assist and support practitioners working with deaf-blind children. Further study and development of valued outcomes for deaf-blind students and the creation and use of tools to measure progress towards educational goals should be a priority for the field.

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Helping Children Cope With Grief: A Discussion of Options for Parents of Deaf-Blind Children

Compiled by
Nancy O'Donnell
Helen Keller National Center

When it comes to parent/child dialogues, there are few topics that cause as much anxiety as sex and death. When those topics are considered in the framework of discussing them with children who are deaf-blind, many families and professionals are left speechless.

Early this year, I received an e-mail from a mother in New Zealand who was looking for guidance on how to help her son grieve the loss of his grandfather:

Hi Nancy,

On Christmas Day my Dad passed away suddenly — and as you can imagine, this has been traumatic for us all — but most of all for Chris [age 31, deaf-blind due to congenital rubella syndrome]. The day after, he came down with the flu and has been in bed since. He is medically much better but emotionally he is not. Do I start getting a little tough and say "You have to get out and about" or do I let him just do his own thing? He also has diabetes so has to have exercise — I just don't know what to do. Thank you. There is no one here to help and doctors don't really understand.

My response was:

My first reaction is that each person grieves in such a different way, you might have to just watch Chris to see how he needs to do this. I personally am not a supporter of the "tough" approach so soon after your loss. What is Chris's communication like? Does he talk? Sign? Draw pictures? Is it just through behaviors that you know how he's feeling? Is your relationship such that you and he can just spend time together doing normal things? Or can you sit with him in his room, hold his hand, just be with him, cry with him? Would it help to take out pictures of your father and look at them and remember? Talk? Reminisce? Give me more information about how you two communicate and maybe I can be more helpful.

In the meantime, make sure that YOU have supports for yourself, to help you through your grieving. I've found that no matter what your relationship was with your parent — good, bad or indifferent — a parent is a parent and the loss is profound. Be gentle on yourself . . . give yourself time and allow yourself to feel all of the feelings that are sure to bubble up. . . . Feelings are tough to deal with and talk about, whether you're deaf-blind or hearing-sighted. But talking about feelings and dealing with them are the key to healing any situation. . . . You're on your way!

The mother responded:

Thank you! Thank you! It's the first time where I have had someone to talk to and who understands in 30 years!!!!!! (apart from family and friends). Chris is totally deaf and blind (he had a little sight but lost it 10 years back). He is a proficient signer in New Zealand sign, Australasian . . . and [uses] the American alphabet, but [talking about] feelings is a hard one. Last night I enticed him out and we . . . bought a life jacket that he desperately wanted and it was a joy to see the smile on his wee face. Today . . . he said he would come down and clean the bath, so I thanked him a hundred times and told him what a kind man he was. We are going away for three days, hoping that makes Chris a little happier.

And later that week:

Last night I sat with Chris and we talked about Grandfather — remembering this and that – and I told him those were the things to remember him with [and] not to think about when he was in the hospital. (Chris was beside Dad when he passed away — what a comfort that must have been for Dad.) Christopher also insisted he was going to [be a pallbearer for] Grandfather.

You have no idea how our family is feeling about this communication we now have with you. In our country, we have very little support. Chris [is] . . . one of a handful of totally deaf-blind living in the community (we had to fight the Government when he was five not to have him put in an institution!!!!!!!). So a big thank you — for the first time, I don't feel so alone.

Through the Helen Keller National Center, we have a group of family members, professionals, and deaf-blind adults who are interested in topics related to those with congenital rubella syndrome. We put the question of grieving and this specific example out to this group. The responses were so helpful and supportive that we decided to share them with the deaf-blind community at large. We hope that these shared insights and experiences will be useful to those who have yet to deal with this difficult topic.

From a mother in New York:

A little over a year ago we lost five family members in one month — my grandmother, two uncles, a cousin, and my brother whom [my daughter] was very close to — then her cat. It was very hard to really know what she was feeling. She doesn't have tears and I never know if she's crying. She would stay in her room, sitting in the chair [and] holding a stuffed animal to replace the cat, or she was in the bed asleep. The staff [at the center she attends] was very helpful because she was able to communicate what she was feeling to someone there. I still am not sure how she is dealing with grieving, but she seems to be doing all right. As a mother, I want to fix everything, but I can't. I need all the help I can get.

From a professional in Massachusetts:

One of my students who is deaf-blind lost her father last fall. We recommended creating a visual schedule of events (wake, service, funeral, pictures of relatives who will be attending the events, etc.) for the days just after the death. The mother also discussed the death and all the events with her and [put together] a photo album [for her daughter to bring back to her program]. Her mother said that our recommendations were helpful and that the

daughter was dealing quite well with her grieving. The daughter was back to her regular schedule on the third day, and she was fine with it.

Keeping busy and getting up and around is an important part of a grieving process. Having regular scheduled events related to the family member who has passed away is also important (special church related memorial activities, grave visits, conversations that are supported by visual or tactile aids, small family ceremonies according with the family traditions, etc.). Talking is helpful but [some] deaf-blind people need concrete objects and specific actions to support them in their grief.

What kind of support is the mother getting at this point? She has lost her father, and she is going through a rough time herself. She has my sympathy, and I hope that she is taking care of herself too.

From a professional in Texas:

Personally . . . I don't trust language too much on this stuff. Demonstrating the rituals that we pursue is where you get started. Who knows what each individual soaks up from these traditions? Much of this is individually tailored . . . even in our hearing-sighted world. Much instruction about death is learned through observation of daily life, and for children it often begins with the passing of a pet. When I was young, we kids, with no suggestions or involvement by my parents, had funeral ceremonies for our pets, complete with little crosses which symbolized to us the protection of the spiritual world. Did we know what the crosses meant? Not really. But the purpose was served.

I think that having a deaf-blind person take part in some aspect of the rituals of their family is what brings them into the experience. It is up to each family to creatively find the best way to become part of the experience. Participation in the ritual is not just for the person . . . but for everyone connected to the person. Death engages us in an experience of closeness with community. Since language is so inadequate, we prescribe rituals to help us experience (celebrate) the needed communion of our lives.

I wonder about the handling of objects which the person used. I personally have such objects, which I keep in a personal "shrine." Perhaps it would be possible to place such objects in a memory box that could be visited to remind the person of the individual they lost. They may be able to relate this to memory boxes, etc., that they have about places they have been.

From a professional in NewYork:

There is no reason why a person with deaf-blindness will not experience loss as profoundly as everyone else. Some time ago, Elizabeth Kubler-Ross outlined stages of grief. . . . It was once thought that everyone had to go through those stages in order. Now, years later, we know that is not true, and that there are other aspects of grief. . . . For a person with limited formal language, the process of explaining what has happened and listening to their feelings can be complicated. The important part is to be there with them and listen empathically. It is especially important that the family and other support people have a common understanding of the language they are using to explain what has happened. For example, has the grandfather "died," "gone to heaven," etc. It would also be important, especially when the deaf-blind person has had a close relationship with the one who has died, to try to understand if they feel in any way responsible or if they have any unfinished business.

As far as how long to allow them to be depressed, idle, sleep, etc., recognizing the feelings of sadness does not mean wallowing in it or allowing it to interfere with the quality of the individual's life. It would be important for the other family members and support people to encourage good nutrition and activity, short walks or favorite outings, etc., while still acknowledging that everyone is sad for their loss. Sometimes, grieving people feel that having fun is a betrayal to their loved one. Time heals, but there is no set amount of time. Also, all those feelings will emerge at different times and be triggered by different events, places and people.

It sounds to me like this young man is very lucky to have such a sensitive and caring mother, who is concerned about him, while grieving herself. I commend her.

From a parent in Washington State:

I have been thinking about the several deaths in our family and trying to recall my daughter's reactions. The person she was closest with was my father, who died when she was six. She attended residential school then. Dad died a week before school began so she was not with her family in the weeks right after he died. On the day he was buried, we selected a plant from the funeral service. We took it to plant outside the window of her classroom. She helped plant it and tend it.

When a family member dies I have my daughter touch the deceased to feel the difference in his or her body. We talk about the things they have done together and that they won't be able to do that any longer. We acknowledge that we are sad. I have included her in as many funerals and memorial services as reasonable so that she has first hand knowledge of the end of a loved person's life. She now understands the

meaning of death and knows that person won't be there to do things with. I don't know if she has ever grieved. I think grieving comes from having expectations that can't be fulfilled. I don't think my daughter has expectations of many people. Compared to others of her age, she has so little control of her life that she fairly well accepts that which comes . . . another one of those mixed blessings that comes from her condition.

I am concerned that the mom soon allow herself to grieve for the loss of her father. We parents have put the needs of our children first for so long that we have become very good at denying our own needs. I suggest [that] she mark a day on the calendar, make arrangements for someone to care for Chris, and clear the deck of other diversions. Planning to spend time reflecting on the joys and sorrows she experienced with her father will help her heal more quickly. Grieving ignored does not go away. It waits and can demand to be dealt with at the most inopportune time.

From a mother in North Dakota:

There were many good responses so far that will be helpful to all of us. My response to this mom will be from a spiritual point. . . . Our son is deaf-blind, low-functioning, retarded, age 35. He lacks patience and has screaming and slapping behaviors, yet . . . sits quietly through an hour and a half church service. There have been many times when I've had to ask the Lord to prepare Jeff for a future event as there was no way I could explain it to him. Jeff has handled many a situation as if someone had explained it to him. Helen Keller said she had always known the Lord, she just didn't know his name. I . . . just wanted to reinforce the immense wisdom and help from our Heavenly Father that passes human understanding.

From a family therapist in California:

On the topic of grieving, I find that all the responses sent in so far are excellent! There has been much written on the topic of bereavement and many good books in the stores. Adapting those ideas and concepts to deaf-blindness is a challenge and all the responses have done so in a beautiful way.

Grief is a natural response to loss of any kind. I would be [suspicious] if there were no grief responses from this young man who has lost a grandfather. His mother is also grieving and her activities (described in her responses) with her son are exactly what they both need at this time. Both mother and son will find it hard in the beginning to define their feeling via language and that is all right. It will come later — just being there physically and sharing with each other quietly will help ease the pain and confusion.

There is no time limit to be set on easing out of grieving. Continuing the activities that have been started between mother and son as well as some of the other suggestions will eventually lead to resolution.

From a mother in Missouri:

My son's father died October 1999. A staff member, who was a very intuitive young man, took Paul to see his dad an hour before he passed. Paul felt his face and held his hand. The young man observed the very different expressions that were occurring on Paul's face and said that on some level Paul knew what was happening.

Perhaps if there is a favorite object from the Grandfather, the young man could keep that as a remembrance. That might help.

And from another mother in Michigan:

After reading the responses on grieving, I decided to add our experience. [My daughter's] father had been ill for many years. He was diagnosed with multiple sclerosis in 1976. For years, he was on a scooter, which she accepted as part of Dad. Later, when the hospital bed became a living room fixture, she knew Dad was there. She would walk over to him, [give him a] big smile, and shake little fingers as her greeting. When he was hospitalized, she'd feel the empty bed but be all smiles when he came home. He passed away at home in April of 1999. We showed her his body, had her feel his face, told her "Daddy bye-bye." We took her to visitation, showed her dad again, saying "Daddy bye-bye." Now, we didn't know how this would register with her but the next morning, when she came into the living room and the hospital bed was gone, she started to sob. I have never before or since heard her sob that hard and long.

Something certainly clicked that morning and her siblings were amazed that she reacted that way. However, [there have been] no more reactions and no objections to going back to her program. As I've learned, we all grieve in our own way and our own time. We were all feeling sad and she probably had extra hugs from all of us.

****

And so, dear readers, we've learned that grieving is grieving, whether you're deaf and blind or sighted and hearing. Everyone does it in their own way, in their own time. There are things that can be done to help the process along, to make it more practical and real, but ultimately, death and loss mean different things to different people. Some of us need more hugs, others need more space. Some of us want to re-

member, others want to forget. But we all need to be respected and allowed to grieve in our own unique way.

Congenital Rubella Syndrome Discussion List

This discussion list has been established as a vehicle for parents, consumers, and professionals to share information about any aspect of rubella and to provide support to those living or working with someone with congenital rubella syndrome.

If you are already registered with Yahoo-groups you can subscribe by sending a blank email to HKNC_Rubella-subscribe@yahoogroups.com. If you are not registered with Yahoo-groups, go to http://www.yahoogroups.com/register. For assistance, contact the owner at: HKNC_Rubella-owner@yahoogroups.com or Nancy O'Donnell at HKRegistry@aol.com.

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Personal Perspectives

Peggy Malloy

"Personal Perspectives" is a column about deaf-blind people, their families, friends, and the people who work with them. This issue features Corrina Veesart, a nineteen-year-old woman who is deaf-blind and her mother Pearl. Corrina and Pearl live in Los Osos, a small community located along the central coast of California. Pearl also has a son, Ryland, who is seventeen. Corrina recently graduated from high school. Pearl works as a professional gardener and landscaper. I talked to Pearl and Corrina about Corrina's educational experiences, her plans for the future, and their feelings about services for deaf-blind people.

Pearl first noticed that Corrina had difficulty seeing and hearing when Corrina was very young. The cause of her deaf-blindness has never been diagnosed, although she has been evaluated by numerous specialists. Initially her hearing loss was believed to be due to central auditory processing disorder, but she was found to be deaf when she was eight years old. Both her hearing and vision loss have been progressive.

Pearl says that obtaining the educational services Corrina needed was often a struggle during Corrina's school years. She learned to be an effective advocate by educating herself in areas of special education law and issues pertinent to deaf-blindness. She has found the network of resources and professionals within the field of deaf-blindness to be invaluable and believes that combining knowledge about the law with those resources can be a potent means of accessing and creating quality services. In this manner she was able to obtain services for Corrina in high school that included a special education teacher with experience and training in deaf-blindness, interpreters, Braille and orientation and mobility instructors, technical assistance and training for specific program needs, and inclusion in typical classrooms. Pearl points out that although special education laws have existed for many years, they aren't always implemented. She believes that it is important for people collectively and as individuals to stand up for their special education rights in order for the implementation of those rights to become commonplace.

Pearl says that her ongoing encounters with the educational system had an impact on her own personality. Although she used to be very shy and easily intimidated, by educating herself and being supported by various professionals, she became empowered and began to feel more confident and assertive. She says that she found her own voice in the process of advocating for Corrina and broke through barriers in herself. She became a healthier and more capable person.

Corrina is both excited and overwhelmed at the prospect of transitioning from school to college and a new life. She echoes her mother's assessment of her school years, when it was often difficult to get what she needed. She says that she is "sick of all the meetings" associated with getting services and would rather be involved in more normal teenage activities.

Corrina can hear an occasional loud sound, but not speech. She also has some vision. She can see a little up close (within five to six inches of her face), but beyond that things are blurry. She says, "I can see shapes further away and often can identify them if I already have an idea what they are. From my window there are two trees in the front yard. I can see the trunk. I can see up to where the leaves are, but I can't make out details. Suppose a bird or a bird's nest is in the tree. I can't tell that unless someone tells me." Corrina mostly uses her vision to see sign language, but says that her eyes get very tired. She feels that her vision is getting worse and she is shifting to tactile sign language.

Corrina plans to go to junior college, but is taking a break from school this fall semester and working instead. She has a part-time job as a teacher's aide in a first grade class. She loves children, especially babies. She might be interested in a career that involves working with children, but she has numerous inter-

ests and at this point in time doesn't know what type of career she will pursue. In high school she enjoyed many subjects, including English, science, and art. She was also a cheerleader for two years.

Corrina loves to read and does so using Braille and large print with a magnifier. She also likes ballet, aerobics, and although she can't hear very well, she enjoys music if she's able to be included through touch. She has friends who are musicians. They let her feel their throats and instruments when they play and sing. During this past summer she took a lot of dance and exercise classes, hung out with her friends, went to visit her dad in Alaska, and attended the Seattle Lighthouse for the Blind deaf-blind retreat.

Corrina says that more than anything she wants space and independence. She says that she can do a lot already, but needs to learn more skills like housekeeping, food shopping, and traveling alone. She wants to be as independent as possible but says that she feels frustrated because, "It seems to be happening so slowly and I feel penned up. I still need to learn so much."

I asked Pearl and Corrina about the current state of deaf-blind services and what they think is important for the future. Both told me that access to interpreters who have the education and experience necessary to interpret for deaf-blind people is very important. They believe that interpreters for deaf-blind people should receive specialized training and recognition.

Pearl had a number of additional observations and suggestions. She said that high-quality assessments are critical because they determine the types of educational services that children receive. She believes that assessments should be performed by people with expertise in deaf-blindness and that parents have a meaningful role in the assessment process. She would like to see quality options for assessment and training available in local communities and says that it is essential to maintain funding of programs and research dedicated to the deaf-blind population.

Pearl said that while she is grateful for the services that are currently available, she believes that there is still much to do to improve the quality of life for deaf-blind people. She says that there needs to be a balance between gratitude and acknowledgment for what the deaf-blind community has and continued efforts to strive for something more. She also says, "Deaf-blind people should have a life with the kind of choices and opportunities that any of us have. That's what Corrina and I are heading for."

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NTAC

National Parent Conference Report

Kathy McNulty

On August 2-4, 2001, in Miami, Florida, a gathering of nearly 150 parents from the United States and Latin America attended *An International Celebration of Empowerment: Sharing Dreams and Visions for Children and Young Adults Who Are Deaf-Blind*, sponsored by the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), along with the National Family Association for Deaf-Blind (NFADB), the Hilton/Perkins International Program, and Foundation ONCE (Organización Nacional de Ciegos Españoles).

The workshop offered a unique opportunity for parents and family members from the United States to exchange perspectives on empowerment and self-determination with parents and families from fourteen Latin American countries. Workshop activities were designed to enhance the capacity of participants to discover and fulfill the dreams of their children and other family members.

Throughout the two-and-a-half days of the meeting, parent and deaf-blind presenters from both hemispheres shared stories about making their dreams come true, the critical need for person-centered planning, and strong collaborative partners, as well as about the importance of balancing the child's dream within the context of the family's dream.

Despite the differences in cultures and backgrounds, parents quickly connected with one another, understood each other's problems and fears, delighted in one another's successes and achievements, and recognized that parents share a universal perspective when it comes to dreaming for their children who are deaf-blind.

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For Your Library

Child Guided Strategies for Assessing Children who are Deafblind or Have Multiple Disabilities (CD-ROM). *van Dijk, Jan & Nelson, Cathy, 2001.*
A CD-ROM that demonstrates assessment techniques developed by Dr. Jan van Dijk. Includes approximately 40 vidoclips of deaf-blind children between two and seven years of age. The CD-ROM is interactive allowing the viewer to test his or her knowledge of a subject. The cost is $50.00. Profits will go into a fund to finance the production of similar materials in the future. Dr. van Dijk says U.S. orders can be sent in care of his brother-in-law, Mr. Joe Franken, 4619 Spyglass Drive, Dallas, TX 75287. Make the check payable to Mr. Joe Franken. Dr. van Dijk's e-mail is j.vdijk@ivd.nl

Collective Wisdom: An Anthology of Stories and Best Practices for Educating Students with Severe Disabilities and Deaf-blindness. *Kansas State Department of Education, 2001.*
A collection of writings by people who have been involved in the lives of children and young adults with severe disabilities and deaf-blindness. Topics include self-determination, collaboration, assistive technology and positive behavioral supports. Available from: Jeff Cook, Kansas Project for Children and Young Adults Who Are Deaf-Blind, Kansas State Department of Education, 120 SE 10th Ave., Topeka, KS 66612-1182. TTY: 785-296-0917. E-mail: jcook@ksde.org

Competencies for Paraprofessionals Working With Learners who are Deafblind in Early Intervention and Educational Settings. *Riggio, Marianne & McLetchie, Barbara A.B. Watertown, MA: Perkins School for the Blind, 2001.*
These competencies address the knowledge and skills that a paraprofessional must have in order to assist in implementing quality programs and enhance the quality of life for learners who are deaf-blind. The cost is $5.00. Available from Public Relations and Publications Department, Perkins School for the Blind, 175 N. Beacon St., Watertown MA 02472. Phone: 617-972-7328.

The Education of Laura Bridgman: First Deaf and Blind Person to Learn Language. *Freeberg, Ernest. Cambridge: Harvard University Press, 2001.*
The Imprisoned Guest: Samuel Howe and Laura Bridgman, the Original Deaf-Blind Girl. *Gitter, Elisabeth. New York: Farrar, Straus and Giroux, 2001.*
Two biographies of Laura Bridgman were recently published. Laura Bridgman was a deaf-blind woman who was born in 1829 and lost both her sight and hearing due to scarlet fever at the age of two. She began attending the Perkins School for the Blind at the age of seven, where she was educated under the direction of Samuel Howe. Both books describe her life, including her education, her complex relationship with Howe in the context of the rapid social and cultural changes that were occurring in 19th-century Boston. Available through bookstores.

Focused On: Social Skills (Video). *Wolffe, Karen E. (Ed.) & Sacks, Sharon Zell (Ed.). New York: AFB Press, 2000.*
FOCUS (Full Option Curriculum for the Utilization of Social Skills) consists of five modules related to helping children who are visually impaired develop social skills. Each set contains a videotape and self-directed study guide. Individual titles: *Importance and Need for Social Skills, Assessment Techniques, Teaching Social Skills to Visually Impaired PreSchoolers, Teaching Social Skills to Visually Impaired Elementary Students, Social Skills for Teens and Young Adults with Visual Impairments.* Each set costs $59.95. Available from AFB Press, Customer Service, P.O. Box 1020, Sewickley, PA 15143. Phone: 800-232-3044. Website: http://www.afb.org/afb_press.asp

Information Packet for New Teachers. *Monmouth, OR: DB-LINK, 2001.*
This packet of information was developed for parents to pass on to their children's teachers (or for teachers to request themselves). It includes fact sheets, newsletters, lists of articles about communication, curricula, and environmental considerations, and a brochure and article that describe DB-LINK services. Available from DB-LINK. Phone 800-438-9376. TTY: 800-854-7103.
Email: dblink@tr.wou.edu
Website: http://www.tr.wou.edu/dblink

Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed.
Moss, Kate & Blaha, Robbie. Monmouth, OR: DB-LINK, 2001.
A book for parents and professionals, this new text offers information and instructional guidance for delivering sex education to deaf-blind students who also have cognitive disabilities. Issues of self-expression related to gender identity, modesty, and appropriate touch are discussed. Specific instruction is included for menstruation, masturbation, hygiene, health, and sexual abuse. Available on the web or by contacting DB-LINK. Phone 800-438-9376. TTY: 800-854-7103.
E-mail: dblink@tr.wou.edu
Website: http://www.tr.wou.edu/dblink

National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives (NTAC Briefing Paper). *Petroff, Jerry G. Monmouth, OR: The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind, 2001.*
This paper describes the results of a study that surveyed parents of deaf-blind youth (age 18-24) who had already left school, to find out about their children's post-school experiences relating to education, employment, living arrangements, and community involvement. Available on the web (http://www.tr.wou.edu/ntac/publications.htm) or by contacting DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: dblink@tr.wou.edu

Research to Real Life: Innovations in Deaf-Blindness. *Leslie, Gail (Ed.). Monmouth, OR: DB-LINK, 2001.*
Research to Real Life presents snapshots of eight research-to-practice projects on deaf-blindness. The projects included research in early intervention, assessment, education, inclusion, communication, technology, behavior, and self-determination. Available from DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: dblink@tr.wou.edu
Website: http://www.tr.wou.edu/dblink

Who Cares?: Access to Healthcare for Deafblind People. *Sense and Deafblind UK, 2001.*
This report is based on a major national survey in the United Kingdom of deaf-blind people's experiences of health care. It outlines actions required to ensure full and equal access to health care for deaf-blind people. Available on the web at:
http://www.sense.org.uk/campaigns/health.html

Announcements

Call for Art Work

The Helen Keller International Art Show sponsored by the Council for Exceptional Children Division on Visual Impairments and the University of Alabama at Birmingham Vision Science Research Center invites youth who deaf-blind, blind, or visually impaired to submit art work. Students may select the preferred art medium. The contest is open to students of all ages.

Art must be submitted by February 1, 2002. The winning entries will be exhibited, beginning with the CEC International Conference in New York City, April of 2002. For more information and to obtain entry forms contact UAB Vision Science Research Center. Phone: 866-975-0624. Fax: 205-934-6722. E-mail: Msanspree@icare.opt.uab.edu

National Federation for the Blind Deaf-Blind Division

The NFB Deaf-Blind Division is an organization of deaf-blind persons working nationally to improve services, training, and independence for deaf-blind people. They offer personal contact with other deaf-blind individuals knowledgeable in advocacy, education, employment, technology, discrimination, and other issues surrounding deaf-blindness. For more information visit the web site at http://www.nfb-db.org or contact:

Joseph B. Naulty, President
561-753-4700
jbnaulty@adelphia.net

Kimberley Johnson, Treasurer
Colorado Center for the Blind
2233 West Shepperd Avenue
Littleton, Colorado 80120
303-778-1130 (ext 212)
eclipse@interfold.com

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Conferences

The Active Learning Approach:
An Educational Approach Facilitating Development and Learning in Children with Multiple Disabilities

Presented by Lilli Nielsen, Ph.D.
November 12-14, 2001
Los Angeles, California

The philosophy behind the active learning approach is that, if given an opportunity to learn from exploration and examination, a child can become an independent active learner. This conference, sponsored by the Infant Development Association of California, in cooperation with WestEd Center for Prevention and Early Intervention will include information about active learning techniques, modifications to the learning environment, and an introduction to perceptual aid equipment. Participants will learn how to give children opportunities to help them develop basic skills in spatial relations, motor development, and emotional and cognitive development. Family members and all early childhood professional disciplines are encouraged to attend.

Contact:
Infant Development Association of California
Phone: 916-453-8801
Email: idaofcal@softcom.net

Eighth Annual Regional Conferences on Improving America's Schools

Three regional conferences by the U.S. Department of Education are scheduled for the Fall of 2001. One has already taken place, but there will be one in Reno, Nevada, November 13-15, and another in San Antonio, Texas, December 17-19. Goals for the conferences include making it possible for participants to gain an understanding of the Department's new priorities and initiatives, learn about the latest research and data, receive information about funding opportunities, and interact and share ideas with Departmental staff.

Contact:
U.S. Department of Education
Washington, DC, 20202-6100
Phone: 800-203-5494
Web site: http://www.ncbe.gwu.edu/iasconferences
E-mail: ias_conference@ed.gov

2001 TASH Conference: Imaging the Future
November 14-17, 2001
Anaheim, California

The TASH conference will include more than 300 sessions on issues that affect the lives of people with disabilities, with a particular focus on those who have severe or multiple disabilities. Panels of presenters include people with disabilities, parents, educators, researchers, and direct support professionals. There will also be exhibits by representatives of many of the leading disability-related manufacturers, publishers, and suppliers.

Contact:
Kelly Nelson
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
Phone: 800-482-8278 ext. 105
Email: knelson@tash.org
Web site: http://www.tash.org

Zero to Three
16th National Training Institute
November 30-December 2, 2001
San Diego, California

The National Training Institute is designed to challenge participants with new ideas and approaches, to provide an opportunity to form connections with others in the infant/family field, and to inspire practitioners in their work with infants, toddlers, and their families.. A pre-Institute is scheduled for November 29th.

Contact:
Meeting Management Services/ZTT
1201 New Jersey Avenue, NW
Washington, DC, 20001
Phone: 202-624-1760
Web site: http://www.zerotothree.org

Autism and Children with Visual Impairment Workshop
Macon, Georgia
February 14-15, 2002

This workshop featuring Marilyn and Jay Gense is being co-sponsored by the American Printing House for the Blind and the Georgia Academy for the Blind.

Contacts:
Janie Humphries
The American Printing House for the Blind, Inc.
P.O. Box 6085
Louisville, Kentucky 40206-0085
Phone: 502-895-2405
Email: jhumphries@aph.org
Web site: www.aph.org

Marie Amerson
Georgia Academy for the Blind
2895 Vineville Ave.
Macon, GA 31204
Phone: 478-751-6096
E-mail: mamerson@mail.gabmacon.org

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- ❑ **Administration (*e.g.*, Dept. of Ed., project director)**
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- ❑ **Technical assistance provider**
- ❑ **Higher education teacher/researcher**
- ❑ **Regular education (non Spec.-Ed.)**
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- ❑ **Teacher trainer**
- ❑ **Government personnel**
- ❑ **Medical professional**
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All issues of Deaf-Blind Perspectives *are available on the Internet at www.tr.wou.edu/tr/dbp* 1001

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Deaf-Blind Perspectives

Volume 9, Issue 2 Winter 2001/2002

The Helen Keller International Art Show An Annual Event

Gail Leslie
DB-LINK

Art shows are full of surprises. Beauty is captured in a combination of colors, images, textures, and objects. The 2001 Helen Keller International Art Show offered many such marvels. Bulging yellow eyes and black handles extending from a sculpted head. A large textured blue tree that dominates the serenity of a collage of grandpa's farm. Kangaroos standing under a large sun in a black and white drawing of the Australian outback. A photograph that capturs the distortion of images layered in a mirrored reflection. One of the show's more surprising elements, however, was not obvious. The artists were children who are visually impaired, blind, or deaf-blind.

The Helen Keller International Art Show is a yearly event sponsored by the Council for Exceptional Children's Division on Visual Impairments (DVI). Under the guidance of Dr. Mary Jean Sanspree, a professor at the University of Alabama Vision Science Research Center and director of the Alabama Deafblind Project, the show has moved from an annual event in Alabama to an international celebration of children's art that travels to galleries and conferences throughout the country.

The show began in 1984 as a project of the Alabama state chapter of DVI. In 1996, Dr. Roseanna Davidson, a professor at Texas Tech University College of Education, became president of the national chapter of DVI. She had seen the show a number of times in Alabama and suggested that the division develop the show as a national project. Since 1996, the invitation to participate has been open to children from all corners of the world who are under 22 years of age and are visually impaired, blind, or deaf-blind. More than 150 pieces of artwork were submitted for the 2001 show. Thirty pieces are selected each year.

The show includes all types of visual art, such as sculpture, collage, and photography. Throughout the year, art fans (families, teachers, professionals, and even members of Congress) have the opportunity to place bids for individual pieces of art that they would like to purchase. During the seven years that the show has traveled, nearly every piece has sold. Dollars generated from those sales go into the budget for the following year's exhibition.

Families and professionals know about the marvelous accomplishments of children who are blind or deaf-blind. The art show gives the rest of the world an opportunity to experience their talents and expressive abilities. Students are able to demonstrate their formidable talents so that others can share in their unique perceptions of the world.

Many people assume that children who have vision loss can only use art forms that are tactual, such as sculpture. In reality, these children can use a variety of media to express their perceptions and experiences through art. One child takes apart toy trucks to feel the shapes of wheels and fenders and reproduces these shapes in a collage. Another student, who is in a wheelchair with head supports, manages to position himself to create detailed artistic strokes that result in a magnificent tiger portrait. "I have seen a child be one inch from the paper and draw the most perfect Ninja turtle," says Roseanna Davidson.

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"You just don't know what they can do until they do it."

Jeff Pruett, a 17-year-old student from Texas, is one of the 30 artists whose work was chosen for the 2001 show. His luminescent portrait of a tiger is entitled *Eyes in the Night*. "Over the years," says Dr. Davidson, "it is hard to imagine all of the things the show has done for families and students. It gives them a chance to participate in a different realm, to participate in art." Dr. Sanspree agrees. "I have known entire families who have flown across the country to see their child's art displayed in the National Cathedral," she says. "This is a group of kids who often don't get recognized or get the rewards." But with participation in the show, they are often featured in their local news and get recognition from their state senators.

The philosophy of the show is that each child is a winner. Each artist who submits a work of art for the show receives a certificate of participation. Those whose work is selected to tour receive artist certificates and a show catalog. To ensure that most of the students get recognized on a local level, U.S. Senators are notified that children in their states have been selected for the show and local newspapers receive press releases.

Dr.Sanspree is the first to express surprise at the show's success and the extent to which it has taken on a life of its own. General enthusiasm for the show

Craig Axelrod, Texas School for the Blind and Visually Impaired (L) and Jeff Pruett (R)

and a willingness to improvise landed the organizers a grand opening for the first national show at the National Cathedral in Washington, DC. Coincidentally, the ashes of both Helen Keller and Anne Sullivan were placed in the National Cathedral. With very short notice, the group built packing crates, organized shipping, and set up the show. Keller Johnson, an Alabama resident and niece of Helen Keller, went along as a volunteer. Another volunteer printed postcards of the artwork to sell to raise money for shipping costs. Suddenly, an event was born. Six years later, the cost of framing and shipping the show is between $5,000 and $10,000 an-

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nually. This covers the regular events that are scheduled each year. Other agencies that would like to have the show displayed at their own locations are asked to cover shipping costs.

Each year the show debuts at the annual Council for Exceptional Children conference. The next six months, from April to September, are typically reserved for touring opportunities. The show has been to galleries at Florida State University, Columbia University, and Texas Tech University. It has been displayed at the National Eye Institute, BellSouth's Corporate Tower in Atlanta, Duke University, and every two years, at the National Cathedral. Each fall it travels to Washington, DC, and is displayed at United States senate and congressional offices until the following July. Usually, the artwork goes to the office housing the senator or representative from the artist's home state. "It's really fun," Dr. Sanspree says of the congressional show. "They are used to having our artwork and they love it. We don't use it as lobbying, we just use it for the kids to have a prominent place to show their work."

Besides the energy and commitment of the DVI committee, the show has benefitted from many dedicated volunteers. Chris Tant runs the Framin' Shoppe in Hoover, Alabama. For a number of years, Dr. Sanspree and others who worked with the Helen Keller Annual Festival were her regular customers. Today, Chris supports their work by supplying materials and expertise. During the year that precedes the show, Chris puts aside miscut or mismeasured frames and mats and saves frames that customers have left behind when reframing their artwork. After she receives the 30 pieces of work for the show, she chooses and cuts the mats and frames for each piece. Then, early one morning, in February, she opens her shop to Dr. Sanspree and a group of volunteers, who mat the work and assemble the frames. By the end of the day the artwork is ready for display. Tant likens this annual event to a mini Santa's workshop but also describes it as something that renews and restores her after the consumer frenzy of the holidays. "It is just something I need every February," she says. "For me, the show is a truly inspirational thing."

People who are involved with children with sensory losses often forget that most people have little experience or understanding of people who have disabilities. The Helen Keller International Art Show creates an opportunity for understanding and sharing the accomplishments of children that one might otherwise never have the opportunity to know. It is an invitation to the unknown. "You can't write off a group of kids because they have sensory deficits," says Roseanna Davidson. "They have to have opportunities and what they produce can really surprise us."

For information about the 2002 Helen Keller International Art Show contact:

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It's Never Too Early
Collaborating With State Early Childhood Programs

Kathleen Stremel
Diane Haynes
John Killoran

Tremaine was born prematurely and weighed just 21ounces at birth. He spent two months in the hospital. At the time he left the hospital, hearing and vision loss as well as additional medical problems had been identified and he was referred to his state's early intervention program for infants and toddlers. Fortunately, early intervention program staff worked with the state's deaf-blind project and together they were able to develop a program to meet his complex needs.

Early intervention services during infancy and early childhood provide a tremendous opportunity to influence the development of children with disabilities, including those who are deaf-blind like Tremaine. Research over the past 25 years has found that infants have a great capacity to learn at a very young age and that social and environmental factors during the early years play a significant role in child development (Sameroff, 1993). In 1986, as part of the Education of the Handicapped Act Amendments (Public Law 99-457), Congress added Part H, a comprehensive program for infants and toddlers, to the Education of All Handicapped Children Act. The act was reauthorized in 1991 as the Individuals with Disabilities Education Act (IDEA). The goal of Part H was to develop and expand state early intervention services for infants and toddlers with disabilities (birth through age two) and their families. In the IDEA Amendments of 1997, Part H was renamed Part C and as of today all states participate in Part C.

Under Part C, each state has a designated lead agency whose purpose is to establish and coordinate a statewide system of early intervention. These agencies are required to provide early intervention services to all eligible infants and toddlers. It is cru-

cial for state deaf-blind projects, families, and other advocates for children and youth who are deaf-blind to be knowledgeable about the specific early intervention systems in their states in order to both benefit from and influence available services. This article describes many of the important features of early intervention services and makes suggestions for expanding and improving these services for infants and toddlers who are deaf-blind.

Resources for Early Intervention

Although all states have systems in place to provide early intervention for children with disabilities, the participation in these systems of people with expertise in deaf-blindness is essential to ensure that infants and toddlers who are deaf-blind receive services that meet their unique needs and learning styles. Their needs are complex. In addition to hearing and vision loss, many also have additional physical, medical, and cognitive disabilities. Many professionals who work in early intervention programs do not have the knowledge and skills necessary to address the needs of these children in such areas as mobility, learning, communication, socialization, and development. Families, state deaf-blind projects, and other service providers working in the field of deaf-blindness can provide the assistance that early intervention programs in their states need to ensure that these young children have:

- the multiple and diverse services they require;
- services that are well coordinated;
- appropriate adaptations to help them access their environments;
- early communication systems; and
- intervention that is included as a part of caregiving routines and family activities.

Many state agencies responsible for early intervention services and training may not be aware of all of the helpful resources available to them through agencies such as the state deaf-blind projects, the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), and DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind.

Characteristics of Early Intervention Services

The Office of Special Education Programs (OSEP), U.S. Department of Education, has funded numerous grants throughout the past 20 years to determine the effectiveness of early intervention services. Guralnick (1997), analyzed these services and found that, in general, successful early intervention programs:

- center on family needs;
- are based in the local community;
- integrate multiple disciplines; and
- plan and coordinate supports and services from numerous agencies.

Although, the systems that provide early childhood services vary from state to state, there are federally established, minimum components that are required under IDEA. These are as follows:

1. Definition of developmental delay;
2. Timetable for ensuring appropriate services to all eligible children;
3. Timely and comprehensive multidisciplinary evaluation of needs of children and family-directed identification of the needs of each family;
4. Individualized family service plan and service coordination;
5. Comprehensive child find and referral system;
6. Public awareness program;
7. Central directory of services, resources, and research and demonstration projects;
8. Comprehensive system of personnel development;
9. Policies and procedures for personnel standards;
10. Single line of authority in a lead agency designated or established by the governor;
11. Policy pertaining to contracting or otherwise arranging for services;
12. Procedure for securing timely reimbursement of funds;
13. Procedural safeguards;
14. System for compiling data on the early intervention system;
15. State interagency coordinating council;
16. Policies and procedures to ensure that to the maximum extent appropriate, early intervention services are provided in natural environments.

(NECTAS)

State deaf-blind projects and other advocates can improve services for infants and toddlers who are deaf-blind, by collaborating with state lead agencies on a number of these components. Because service characteristics are not uniform for all states, it is important to be knowledgeable about your own individual state system. Some key features of effective early intervention services are described below.

Early identification and referral. It is critical that infants with combined vision and hearing loss be

identified and referred for services as early as possible. If infants are not identified, they can not be served. If they are not served, their risk for developmental delay is increased. Many are born very prematurely or have syndromes associated with serious medical issues. Health care professionals often concentrate on the medical issues rather than on the impact of sensory loss on development.

Census data collected on infants and toddlers who have combined vision and hearing loss indicate that few infants are identified and referred for early intervention services prior to one year of age. It is important that infants who are at risk for vision and hearing loss, such as very low-birth-weight infants, receive vision and hearing screenings before leaving the hospital.

All states are required to have comprehensive child find services in place to identify, locate, and evaluate children with disabilities. State deaf-blind projects should be knowledgeable about how child find systems operate in their states and they should establish linkages with involved agencies to assist in the early identification of infants who are deaf-blind.

Natural environments. IDEA requires that "to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate" (Code of Federal Regulations, 1999, §303.12(b)). A justification must be made for the "extent, if any, to which the services will not be provided in a natural environment" (§303.344(d)(ii)). Provision of services in the natural environment alone, however, is not enough. The techniques used must be effective ones. These include making use of typical events, activities, and routines in a variety of settings to teach a range of skills; providing interactions that focus on the child's engagement and interests; and using strategies that are nonintrusive and are appropriate for each child's developmental stage and unique abilities (Warger, 1999).

Individualized family service plans. The individualized family service plan (IFSP) is the process by which a family and an IFSP team determine the outcomes that they would like to see for the child and the family. The IFSP must address service coordination, natural environments, and transition to preschool. IDEA regulations outline 16 different services (e.g., assistive technology, physical therapy, audiology, vision services) that may be included under early intervention services, but these services are not exhaustive (Code of Federal Regulations, 1999, §303.12). Each child and family eligible for services must be provided with a service coordinator.

Central directory. Each state must have a central directory of information about state early intervention resources and services, that is accessible to families and service providers. State deaf-blind projects and other agencies providing services to children who are deaf-blind should make sure that they are listed as resources in this directory. They should also make sure that they have access to the central directory and use it as a resource.

State early childhood technical assistance systems. Many states have developed early childhood technical assistance programs to provide training and support to early childhood providers (NECTAS). Technical assistance is essential because teacher-training programs in colleges and universities do not adequately prepare teachers to provide effective early intervention services (Kilgo and Bruder, 1997).

Suggestions for Participating in Statewide Early Intervention Systems

There are many ways that state deaf-blind projects and other advocates can participate in statewide early intervention systems and work to improve outcomes for infants and children who are deaf-blind.

- Become a part of your state lead agency's public awareness program. These programs focus on raising awareness about the importance of early identification of infants and toddlers with disabilities and the availability of early intervention services.
- Attend Interagency Coordinating Council (ICC) meetings. State ICCs are comprised of a variety of individuals and agencies appointed by the governor, including parents and service providers. Their purpose is to advise and assist lead agencies regarding aspects of early intervention services.
- Invite a member of your state's lead agency to be a member of your advisory committee.
- Share materials about deaf-blindness with your state's lead agency and parent training and information center.
- Be aware of the knowledge and skills that are most needed by direct service providers and parents and inform them about the needs of children who are deaf-blind.
- Be aware of your state's Comprehensive System of Personnel Development (CSPD) plan and serve as a resource to state early intervention training programs.
- Network with families. State deaf-blind project family specialists can provide information and support or serve as mentors to families.

Summary

There is strong support for a connection between early intervention and learning experiences and later school and work performance (Sandall, McLean, and Smith, 2000). Identifying children who are deaf-blind and starting services as early in life as possible are crucial in order to give each child the best possible opportunity to learn and develop. State deaf-blind projects and others involved in the lives of children who are deaf-blind can play an important role by assisting state early intervention systems to meet the unique needs of infants and toddlers who are deaf-blind.

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Technical Assistance to Early Childhood Providers in Kentucky

The following are examples of technical assistance activities used by Kentucky Services for Children and Young Adults Who Are Deafblind:

- Various local, state, and regional training opportunities (topics determined based on evaluation of participants' needs).
- Printed information (topical papers, brochures, newsletter) to update families and service providers about resources, upcoming events, and best practices.
- Regular, ongoing contact with families by telephone to find out how they are doing and determine whether they have a particular need that might be addressed by the project.
- Reach for the Stars, a specific training initiative designed to help families and service providers use a person-centered approach to plan a young child's transition from early intervention to preschool and from preschool to primary school.
- Close collaboration with the state's lead agency and other major service providers in the state to improve early identification of children who are deaf-blind (this has resulted in a significant rise in the number of referrals of children, from birth to age two, who have been referred to the project).
- Training of service providers to teach receptive and expressive communication skills to persons who have severe and/or multiple disabilities including deaf-blindness (the project received Comprehensive System of Personnel Development (CSPD) funds to develop and provide this training).
- Development and coordination of a university course, Severe Handicaps Integrated Preschool Programming, funded by a grant to the project from CSPD and Part B 619 funds (individuals serving children on the state deaf-blind project census are given first priority to attend the course).
- Development and teaching of other university and distance-learning courses as part of Kentucky's State Improvement Grant activities on the topic of natural environments.
- The use of project staff as trainers on four statewide early childhood training teams, giving them an opportunity to share valuable information about deaf-blindness and to conduct child find activities.

Update on the IDEA Reauthorization Process

Joe McNulty
Director, Helen Keller National Center
Co-Chair, National Coalition on Deaf-Blindness

Over the past few months, the U.S. Department of Education, along with interested parties within the disability and general education communities, has begun to plan for the reauthorization of the Individuals with Disabilities Education Act (IDEA). Active involvement in the process by people in the field of deaf-blindness will be important in order to ensure that services addressing the needs of deaf-blind children are included in the new law. This article discusses provisions specific to deaf-blindness currently included in IDEA as well as some of the issues that will be important for the reauthorization.

IDEA 1997

Educational services for deaf-blind children have been part of the Department of Education's special education programs for more than 20 years. Prior to the reauthorization of IDEA in 1997, a deaf-blind program was one of fourteen discretionary programs found in the Act. The program received $12.86 million per year to support deaf-blind projects including NTAC, DB-LINK, and several demonstration projects. During the 1997 reauthorization, however, those fourteen discretionary programs were collapsed into five broad categories and placed in Part D, National Activities to Improve Education of Children with Disabilities, of the new Act. The five categories are coordinated research, personnel preparation, technical assistance, support, and dissemination of information.

Although services previously provided under the deaf-blind program could easily fit into the technical assistance category found in Part D, there was no guarantee that the existing projects in deaf-blindness would continue to be funded, nor was there a provision to ensure that money would be made available for deaf-blind specific programs. Fortunately, the National Coalition on Deaf-Blindness was able to secure language in several sections of the Act to protect both the structure of the deaf-blind program and its funding. Of greatest significance was Sec. 661, Administrative Provisions, which includes a minimum funding requirement to ensure that at least $12,832,000 be provided to "address the educational, related services, transitional, and early intervention needs of children with deaf-blindness."

While the minimum funding language mandated that the Department of Education spend $12.8 million on deaf-blind children, how they spent the money remained a major concern. Here again, specific references to deaf-blindness within the Act helped shape the services. The definition of a "low incidence disability" found in Sec. 673, Personnel Preparation, includes "a visual or hearing impairment or simultaneous visual and hearing impairments." Sec. 685, Coordinated Technical Assistance and Dissemination, lists examples of the types of activities that may be carried out under national information dissemination, including "services for populations of children with low-incidence disabilities, including deaf-blind children, and targeted age groupings." In the same section, under Specialized Technical Assistance, authorized activities include those that "focus on needs and issues that are specific to a population of children with disabilities, such as the provision of single State and multi-State technical assistance and in-service training . . . to schools and agencies serving deaf-blind children and their families."

In July of 1998, approximately one year after IDEA '97 was signed into law, several dozen representatives from national, state, multi-state, and university or demonstration projects in the field of deaf-blindness, as well as consumers, parents, and state education agency staff, met in Alexandria, Virginia. The goals of the group were to identify key issues in the education of children and youth who are deaf-blind and to provide the Department of Education's Office of Special Education Programs (OSEP) with input from the field on directions for federal support. Taking into consideration the recommendations from the focus group and following the language found in IDEA '97, the OSEP staff kept the structure of the old deaf-blind program and has since held competitions and awarded grants to provide national technical assistance, state and multi-state technical assistance, and personnel preparation.

IDEA 2002

The Department of Education recently completed a series of seven public forums to solicit comments on the upcoming reauthorization to be considered during the administration's drafting of the new bill. Although the National Coalition on Deaf-Blindness (NCDB) has not developed a formal position statement at this time, testimony provided by parents, professionals, and students on behalf of the deaf-blind programs focused on several key issues including the following:

Maintain the minimum funding language in Sec. 661. In my opinion, this is the linchpin of the entire network. Without this requirement, I do not believe the Department of Education would continue to place the same financial resources into the education of deaf-blind children and, consequently, services at the state and local level would be dramatically reduced, if not eliminated entirely.

A second, but very important, part of this particular issue is to get the minimum-funding amount increased significantly. In 1976, there were 4,600 children with deaf-blindness who benefited from the services provided by ten regional centers. At that time children were educated primarily at state schools for the blind or another type of residential program. The funding level was $16 million. Over 10,000 youngsters are currently being served, primarily by local education agencies (LEAs). The need for the technical assistance provided by the deaf-blind projects has never been greater but the funding has remained at $12.8 million for the last ten years.

Maintain the thirteen existing disability categories, including deaf-blindness. During the 1997 reauthorization process, there was some discussion about eliminating the categories. Those in the field of sensory impairment felt, and continue to feel, that the identification of the disability (deaf-blindness, deafness, hearing impairment, visual impairment including blindness) was, and is, an important factor in securing proper educational services for children.

Improve the definition of a child with deaf-blindness. As it's currently written, the definition is extremely limiting and excludes nearly 85% of children being served by the state projects.

Full funding for all parts of IDEA. In an attempt to fulfill its pledge to pay for 40% of the cost of special education, the federal government has approved large increases in the funding of IDEA over the past few years. Unfortunately, none of the additional money has gone into Part D. While it's imperative that the LEAs receive adequate financial support from Washington, the additional money will do the children little good without the coordinated research, personnel preparation, technical assistance, support, and dissemination of information provided by the projects funded through Part D. This recommendation is tied directly to the request to increase the minimum funding level found in Sec. 661.

It is expected that Congress will pass a one year extension of IDEA, which means that it will come up for reauthorization in the fall of 2003. During the next 18 months, the National Coalition on Deaf-Blindness will continue to be actively involved with a number of other groups, including the Consortium for Citizens with Disabilities, as it advocates for improvements in educational services for all children with disabilities.

Strategies for Postsecondary Educational and Support Service Personnel Serving College Students With Usher Syndrome

Patricia Lago-Avery

Usher Syndrome is a genetic disorder characterized by congenital hearing loss and gradually developing retinitis pigmentosa that leads to loss of vision. It is estimated that the syndrome occurs in 4.4 of every 100,000 people in the United States (Boughman, Vernon, & Shaver, 1983). The two most common types of Usher Syndrome are type I and type II. Type I Usher Syndrome is characterized by congenital deafness, vision problems beginning in early childhood, and balance problems. Type II is characterized by moderate-to-severe hearing loss and night blindness that typically begins during childhood. Historically, most students with Usher Syndrome type I attended residential schools and colleges for the deaf, while those with type II attended regular public schools and universities. With the mainstreaming of deaf and hard of hearing students brought about by Public Law 94-142, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act, students with Usher Syndrome now attend school in all types of educational settings. It is critical for support service personnel and counselors in college and university environments, who provide career, personal, and mental health counseling to students with Usher Syndrome, to have a good understanding of special issues that arise for these students and to be aware of strategies that will be of benefit when working with this population.

College age students who have Usher Syndrome face the same developmental issues encountered by most adolescents and young adults. However, they also have educational, personal, and social concerns that are not encountered by students who have normal hearing and vision or even by their deaf and hard of hearing peers with normal vision. Orientation and mobility skills to negotiate travel around campus, communication in the classroom and with peers, career considerations, and the ongoing process of adjustment to changes in hearing and vision

loss are some of the Usher-specific challenges faced by these students.

The first priority in a postsecondary educational environment should be to conduct an interview to complete an educational needs assessment. Do not assume that the student is already knowledgeable about Usher Syndrome. Assess his or her knowledge about the medical aspects of Usher Syndrome as well as about services available to people who have Usher Syndrome. Questions you may wish to ask include:

- Do you have trouble finding your way around in new places? Can you hear or see the fire alarm in your dorm room? Can you see in dimly lit places?
- Do you have trouble reading the blackboard? Is it easier for you to read whiteboards with black markers?
- Do you have a problem with glare from overhead projectors or in the classroom?
- Do you have difficulty reading regular printed materials? Does it help to have a larger font size such as 18- or 24-point? (Show the student examples of different font sizes.)
- Are you able to visually follow your interpreter in the classroom? Is his or her use of space outside of your vision range?
- Are you having difficulty hearing in the classroom or in situations where there is a lot of background noise?
- Can you follow group discussions?
- Do you have any concerns about your chosen career and your future?

Once you have completed the needs assessment, you can begin to help the student address issues related to optimizing the educational environment. You are also establishing a foundation on which subsequent personal and social issues can be considered.

Educational Issues

Orientation and mobility. Some students may need orientation and mobility training. Many, for example, will have a difficult time finding their way around campus or the surrounding community at night because of night blindness. Locate orientation and mobility services in your community by contacting your state commission for the blind. If there are no services available in your community, find out if they are available in the student's hometown.

Classroom visual adaptations. A variety of techniques can be used to make it easier for students with Usher Syndrome to see visual information presented in the classroom. It is important to find out which adaptations work best for a particular student. Adaptations include the following:

- Good lighting that does not produce glare.
- If blackboards and whiteboards are used, find out which works best for a particular student. Some may need a notetaker to take notes for them.
- When using overhead projectors, use an 18- or 24-point font on transparencies and distinct color combinations for good contrast (e.g., black on white, black on yellow, or white on dark blue). Yellow transparencies may help to reduce glare. Provide the student with paper copies of transparencies.
- Technology has greatly enhanced learning opportunities for individuals who are blind or visually impaired. Investigate the possibility of providing a CCTV (closed circuit television) for reading books and handouts from the instructor. Computers that take advantage of adaptive technology for blind and visually impaired individuals are also of great benefit. If the student needs this type of equipment for success in the classroom, he or she will need it for success in life as well. Work with the student's sponsoring agency to secure necessary funds.

Communication in the classroom. The use of an interpreter is very important for students who use sign language. If the student is attending a college where the faculty and students all use sign language, use of a copy interpreter (someone who sits within the visual range of the student and repeats what has been signed or spoken) may be beneficial. If the student is in a setting where sign language is not commonly used, an interpreter notetaker and may be necessary. If the student does not use sign language and depends on lipreading and residual hearing, use of a notetaker is critical. These students may also require an oral interpreter.

Career Issues

Career choice is an important concern for deaf-blind students. The impact of vision loss may be a consideration for some types of careers, but it is hard to predict how each person's vision might change as he or she ages. Educate yourself about the types of careers that deaf-blind people have and encourage the student to research career options as well. Currently, one can find people with Usher Syndrome working in the following professions: researcher, professor/author, chef/owner of restaurant, law-

yer, certified public accountant, information technology specialist, computer programmer, public health manager, counselor/professor, minister, librarian, veterinarian, health planner, clerk, medical transcriptionist, mental health counselor, high school teacher.

Students with Usher Syndrome study a wide variety of subjects in college. In 1995, research was conducted at the National Technical Institute for the Deaf analyzing data compiled by Dr. Don Johnson (then director of the NTID Eye and Ear Clinic) regarding the number of students with Usher Syndrome who had attended Rochester Institute of Technology/National Technical Institute for the Deaf. RIT was founded in 1829 and is a privately endowed coeducational university that includes seven colleges. One of these colleges is the National Technical Institute for the Deaf. Between the academic years of 1984 and 1995, 62 students with Usher Syndrome entered the colleges. At the end of this period of time, 21 students were currently enrolled, 20 had already graduated, and 21 had either withdrawn or taken a leave of absence. At first glance the number of students who withdrew or took a leave of absence might seem high, but the percentage is actually much lower than the national attrition rate of fifty percent (Brawer, 1996). In comparison, two-thirds of the students with Usher Syndrome who were enrolled at RIT/NTID during the period 1984 to 1995 stayed in college or had already graduated. These numbers speak very highly of the motivation and skill level of students who have Usher Syndrome. Moreover, they suggest that students' educational support and service needs were positively considered.

Personal and Social Issues

Adjustment to Usher Syndrome. The process of adjustment to Usher Syndrome is ongoing. For students who are struggling academically and/or emotionally, it is important to gently try to help the student understand that changes in vision and hearing may be impacting his or her ability to function in the classroom or with peers. If a student is unwilling to talk about these issues or is depressed, angry, and afraid, he or she may need more in-depth mental health counseling. If you feel you are not qualified to work with students who have these types of problems, locate a qualified therapist to whom you can refer the student. If a student is resistant to your assistance or to assistance from others, it is important to understand that this type of student might fail. Professionals are trained to try to prevent failure, but sometimes failure is needed before a student is willing to make changes in his or her life.

Communication with peers. If a student is having problems communicating in group settings or dark places, encourage the student to be more open about having Usher Syndrome, to talk about communication needs with close friends, and to learn alternative communication strategies.

Role models. If possible, try to find a person who has Usher Syndrome who can function as a role model and mentor for the student. Encourage students to meet other people who have Usher Syndrome, especially adults who have learned how to adapt and make modifications in their lives that enable them to function well and independently. There are also e-mail discussion groups available where people with Usher Syndrome can share their experiences (see resource list).

Working with Students Who Are Unaware They Have Usher Syndrome

Although professionals who work in the field of deaf education are becoming more aware of Usher Syndrome, there are still a number of students who arrive at the doors of colleges and universities unaware that they have Usher Syndrome. Some students have already lost a significant amount of vision while others have not yet experienced enough vision loss to warrant their attention. You may notice that a student misses some of your signs, doesn't seem to understand what you are saying, or may not respond when you try to catch his or her attention. If you suspect a student might have Usher Syndrome, tread with caution. How you handle this situation could either enhance your relationship with the student or cause harm. If you are not comfortable dealing with this type of situation, then consult with other professionals and bring in someone to assist you. The following suggestions are based on my professional experience working with several students who did not know they had Usher Syndrome when arriving as freshmen in college.

Ask if the student has a vision problem. If the response is yes, ask what he or she knows about the vision problem. It might be a great deal. If the response is no, then you might share your observations. For example, "I noticed that you do not always see me when I am trying to get your attention," or "When I am signing, I notice that you miss some of my signs." Sometimes a student does not know that he or she is missing things in the environment or the classroom. That is why your observations are important. If the student seems unsure of your examples you might want to ask if he or she has trouble

seeing in the dark or in dimly lit places or bumping into objects. If the response is yes to any of these questions, then it is important to strongly recommend an evaluation by an ophthalmologist who specializes in retinal diseases. Do not tell the student that you think he or she has Usher Syndrome. That is not your role. The student might not even have a vision problem or might have a different type of vision loss. Your role is to help facilitate the process and to encourage the student to have a thorough vision evaluation.

If the student agrees to have a vision evaluation, your next step is to work with the student and perhaps with his or her parents (with the student's permission) to find an ophthalmologist knowledgeable about retinal diseases. If the student is fully independent and prefers to handle the situation independently, then just work with the student. If you do not know where to find a specialist, you can call the Foundation Fighting Blindness (see resource list). Another option is for you to suggest that the student or parents request a referral from the family doctor. The most important role you can play in this type of situation is that of facilitator.

How do you involve the parents? You should not tell the parents that you suspect that their child has Usher Syndrome. But you can say, "In my work with your daughter/son I have noticed several things that lead me to believe that he/she may not have optimal vision use. It seems that your son/daughter might be experiencing some difficulties seeing in the dark or might have some visual field gaps." With this said, then you could strongly encourage the parents to make arrangements for their child to be seen by a retinal specialist.

How do you help the parents/doctor/student once the diagnosis is confirmed? Again, your most important role is as a facilitator. It is critical to help them find people who can clearly explain what is meant by Usher Syndrome, what the implications are, what the future holds, and how the family and student can get assistance. Doctors can give a diagnosis but more often than not, that is where their help stops. The student and parents need much more than a diagnosis. They will have many questions, they may be in shock, they might ignore the diagnosis, or they might seek out second, third, or fourth opinions, which is their right.

Conclusion

Working with college age students who have Usher Syndrome presents challenges for postsecondary educators and support personnel. It's possible to feel overwhelmed, but it's important to keep things in perspective and remember that students with Usher Syndrome are more like their peers than they are different. They have the same educational, social, and psychological needs as other adolescents. It is essential to focus on an *individual* student's unique needs in order to help him or her become successful in life. I emphasize the word "individual" because we are all different in our needs and our perspectives on life. We owe students with Usher Syndrome respect for their individualism and need to keep this in mind when providing services.

Resources

For more information about Usher Syndrome, contact DB-LINK. Additionally, information about Usher Syndrome and links to other websites can be found at the DB-LINK Website.

DB-LINK
The National Information Clearinghouse on Children Who are Deaf-Blind
Teaching Research Division
Western Oregon University
345 N. Monmouth Avenue
Monmouth, OR 97361
Phone: 800-438-9376
TTY: 800-854-7013
FAX: 503-838-8150
Email: dblink@tr.wou.edu
Web: http://www.tr.wou.edu/dblink

Other Organizations and Agencies

American Association of the Deaf-Blind
814 Thayer Avenue Ste 302
Silver Spring, MD 20910
TTY: 301-588-6545
FAX: 301-588-8705
E-mail: aadb@erols.com

Foundation Fighting Blindness
11435 Cronhill Drive
Owings Mills, MD 21117-2220
Phone: 888-394-3937
TTY: 800-683-5551
Email: info@blindness.org
Web: http://www.blindness.org

Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)
111 Middle Neck Road
Sands Point, NY 11050-1299
Phone: 516-944-8900
TTY: 516-944-8637
E-mail: hknctrng@aol.com
Web: http://www.helenkeller.org/national

Usher Syndrome Project
Boys Town National Research Hospital
555 North 30th Street
Omaha, NE 68131-9909
Phone & TTY: 800-835-1468
E-mail: genetics@boystown.org

E-mail discussion groups

DBTeens
An e-mail Internet forum for teens and young adults who have Usher Syndrome or who are deaf-blind, to share information, ideas, and opinions. This is a private list for teens and young adults. To subscribe, contact Randy Klumph at klumphr@wou.edu. Send the message "subscribe DBTeen."

Usher Syndrome List
An Internet forum for people with Usher Syndrome, their parents, friends, spouses, and service providers. To join this list send a blank email to: Ushers-subscribe-request@tr.wou.edu, or contact Randy Pope, ushers-request@tr.wou.edu

References

Boughman, J. A., Vernon, M., & Shaver, K. A. (1983). Usher Syndrome: Definition and estimate of prevalence from two high-risk populations. *Journal of Chronic Disabilities* 36 (8), 595-603.

Brawer, Florence B. (1996) *Retention-attrition in the nineties*. ERIC Digest. Report No. EDO-JC-96-06. ERIC Document Reproduction Service No. ED 393 510. Los Angeles: ERIC Clearinghouse for Community Colleges.

Author Information

Patricia Lago-Avery is a retired counselor and professor from the National Technical Institute for the Deaf/Rochester Institute of Technology. She has worked with deaf and hard of hearing students for over 26 years, 23 of those at NTID. The information in the above article is based on her many years of experience working with college students who have Usher Syndrome as well as her own personal experience with Usher Syndrome type II. She can be contacted at pllnbu@rit.edu or via her Web site, LA Consultants at http://www.rit.edu/~pllnbu

Note: Ms. Lago-Avery wrote a longer version of this article that will be published on the PEN International Web site (www.pen.ntid.rit.edu) at a future date. PEN-International is a program funded by The Nippon Foundation of Japan at the National Technical Institute for the Deaf, Rochester Institute of Technology .

It Sounds Nice, But Is Inclusion Really Worth It?

Nancy Hartshorne, Ed.S.
Parent and School Psychologist

At a National Technical Assistance Consortium for Children and Youth Who Are Deaf-Blind (NTAC) workshop about inclusive practices held last year in San Diego for the state deaf-blind projects, many people approached me and asked for my "parent" perspective about how inclusive education works for my son. Jacob is 12 years old and is in sixth grade. He has CHARGE syndrome and is deaf-blind. What are the advantages of his inclusive placement? Is it really worth the time and effort? What have been the outcomes? Here is my answer to these questions.

Jacob has a label of Severe Multiple Impairments (SXI). Without our intervention, he would have remained in the local SXI classroom. In this classroom, from age three to age five, Jacob was completely segregated from peers without disabilities. All supports and services were provided right in the classroom. The students even had lunch there although the classroom is housed within a local elementary school. Activities were individualized, but taught to him separately from other children so socialization did not take place even between the students in the classroom. Most were not able to move independently. Jacob's only meaningful contact at school was with adult service providers. Skills were taught in artificial rather than natural contexts. For example, physical therapy consisted of exercises practiced by rote in the classroom. Jacob used a walker to walk five feet across the classroom floor and then was instructed to turn around and walk back. Language was taught in thirty-minute pullout sessions two times per week.

Jacob's current program takes place in his neighborhood elementary school. He has attended this school with his same-age peers since kindergarten. His education is individualized and takes place in natural contexts. Physical therapy takes place during P.E., recess, track meets, and Field Day practices. The occupational therapist's oral motor objectives are carried out during lunch in the cafeteria. Language is taught and practiced throughout all activities of his day. With his classmates, he attends his sixth grade classroom, art, music, P.E., library, recess, and lunch, with the help of a one-on-one intervener. He has participated in school plays and music concerts, auditioned for and performed in the talent show with his friends, and was a cub scout. He has a strong, active circle of friends. At age seven, he

walked independently for the first time. He got up from his desk, walked out of his classroom, down the hall, out the school door, and to his bus to go home. Students clapped and cheered. Many of the teaching staff had tears in their eyes. Everyone celebrated Jacob's achievement with him.

If Jacob had spent the past seven years in the SXI classroom, I believe his outcomes would have been vastly different:

- He would not be walking independently. He would have nowhere to go.
- He would not be using his five manual signs. He would have no one to talk to.
- He would not be locating places and using mobility routes independently, based on object-picture cues. He would have no routes to use or locations to find.
- He would not have met nearly every single IEP objective each year. He would have had little motivation to do so.
- He would not be invited to birthday parties. He would have no friends.
- He would not have his annual "Birthday Swimming Bash." He would have no one to invite.
- He would not have earned The Arrow of Light, the highest honor that a cub scout can earn. He would not have attended campouts. He would not have won two second-place trophies for speed and one first-place trophy for design in the pinewood derby because he would not even have made a car.
- He would not have independently carried out the role of The Star of Bethlehem in the church Christmas pageant for the past two years. No one would have expected that he could play a part, and no one would have asked him to.
- He would not have participated in the school talent show with his circle of friends. No one would have recognized that he had any talent.
- He would not have the constant support of 18 friends without disabilities in the sixth grade, his Circle of Friends. He would have no friends. He would have no one to advocate for him in ways such as these:

Sarah, age 10, who explained the importance of inclusion and circles of friends on camera:

> **Sarah**: "Our circle is important because we help Jacob participate in everything the other kids do."
>
> **Interviewer**: "And why do you see this as important?"
>
> **Sarah**: "'Cause if he didn't participate with his friends, he'd just come to school and be with teachers all day. No one wants to be with teachers all day—that's no fun."

Justin, age 10, who was nominated for and received a district-wide Martin Luther King peacemaker award for assisting Jacob during a music concert at school. He refused to attend the ceremony or to accept the award, saying, "I was just being his friend—I shouldn't get an award for that!"

Creativity, high energy, collaboration, and thinking "out of the box" have been key characteristics of Jacob's team members. Even so, Jacob's inclusive program is far from perfect. His team struggles with making the sixth grade textbook curriculum meaningful for him. He still spends significant time away from his peers as he works toward independence in the bathroom, receives tube feedings, and is pulled out for some auditory training and specific language therapy. However, this program has been well worth the effort and advocacy on our part. Jacob continues to be happy and motivated to learn, to gain skills, to receive and give social support, and to surprise everyone on a daily basis. And the benefits to his friends without disabilities have been too numerous to count.

The alternative—a segregated, lonely, and hopeless educational track—is unthinkable.

Jacob belongs, and he knows it. He has a community, and he knows it. That is quality of life.

Registry of Interpreters for the Deaf

Deaf-Blind Special Interest Group

Susanne Morgan, M.A., C.I., C.T.

Exciting events are happening within the Registry of Interpreters for the Deaf (RID). A Deaf-Blind Special Interest Group (DB SIG) that focuses on the interests of interpreters who work in the field of deaf-blindness has been in existence for several years and is now working to expand its membership and activities. Susanne Morgan (NTAC Technical Assistance Specialist) and Angela Lampiris (HKNC Coordinator of Interpreting Services) were chosen as the new chairpersons of the group at a recent RID conference. Carolyn Jolley has been the secretary and will continue in this role. Planning for the upcoming year is currently underway. Goals include the following:

Membership networking and expansion. Increase the number of members, encourage demographically diverse representation, and expand leadership.

RID Views Column. Post updates and share information in *Views* (RID's monthly magazine).

DeafWayII. This is an international event for the Deaf that will be held at Gallaudet University in July 2002. Work with the DeafWayII Deaf-Blind Interpreter Coordinator Team to advertise the event to deaf-blind individuals and to recruit interpreters and support service providers (SSPs).

Deaf-blind standard practice paper (SPP). Work with the American Association of the Deaf-Blind (AADB) to complete this document, which has been in development for several years and is nearly ready for distribution. The paper shares some best practices in the field of deaf-blind interpreting and has been revised over the past several years based on input from representatives of the deaf-blind interpreting community and AADB. When finished, it will be available on the RID Web site (www.rid.org).

DB SIG Web page & e-mail discussion group. Create a DB SIG Web page that can be accessed via the RID Web site. Investigate the level of interest in and possibility of developing an e-mail discussion group for DB SIG members to share information and network.

Information sharing about interpreter training workshops. Develop a way for interpreters and interpreter trainers to share information about workshops they are doing related to deaf-blind interpreting.

Pre-conference at RID national conference in Chicago, 2003. Host a pre-conference session at the next national RID conference to increase awareness of deaf-blindness and the number of skilled deaf-blind interpreters.

Mentorship proposal. Review a proposal by Leslie Foxman (a former DB SIG chairperson) to provide mentorship opportunities for interpreters interested the field of deaf-blind interpreting. This pilot program will begin at the 2003 American Association of the Deaf-Blind (AADB) National Conference in California. It will provide an opportunity for students currently enrolled in interpreter-training programs to work directly with mentor interpreters and deaf-blind people.

National Interpreter Education Project. Promote discussion about the use of a new curriculum designed to train interpreters to work with deaf-blind people, which was recently developed by the National Interpreter Education Project at Northwestern Connecticut Community College.

As time goes by, interest, recognition, and support by national organizations for the needs of individuals who are deaf-blind, their support persons, and interpreters increases. As a community we can achieve much more, and the Deaf-Blind Special Interest Group wants to be a part of this. Contact us if you have questions or would like additional information.

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Usher Syndrome Research Project

This study is trying to find the genes responsible for Usher syndrome in Ashkenazi Jews. Individuals (or their family members) of Ashenazic heritage who have Usher syndrome, or both hearing and vision loss that has no other known cause, may be eligible to participate.

For more information contact:
Dr. Seth Ness
Department of Human Genetics
Box 1497
Mount Sinai School of Medicine
One Gustave L. Levy Place
New York, NY 10029
Phone: 212-241-6947
E-mail: nesss01@doc.mssm.edu

For Your Library

American Association of the Deaf-Blind 2001-2002 Deaf-Blind Contact Directory
This directory contains listings for AADB members, support service providers, state and local associations for deaf-blind people, services, and distributors, and manufacturers of assistive technology and products. Available from American Association of the Deaf-Blind, 814 Thayer Avenue, Suite 302, Silver Spring, MD 20910-4500, 301-588-6545 (TTY), 301-588-8705 (Fax), aadb@erols.com.

Creative Expression: Opportunities for Persons who are Deafblind (Video & Booklet) *Terre Haute, IN: Indiana Deafblind Services Project & Madison, WI: Bailey Video Design, 2001.*
This video, produced by DB-LINK, The Blumberg Cen-

ter, and VSA Arts of Indiana and a booklet, produced by Indiana Deafblind Services, present ways to involve deaf-blind people in creative arts including music, painting, pottery, weaving, and writing. The video is available for loan from DB-LINK, 800-438-9376, 800-854-7013 (TTY), dblink@tr.wou.edu. The video and booklet are available for purchase from the Indiana Deafblind Services Project, Blumberg Center, Indiana State University, School of Education, Rm 502, Terre Haute, IN 47809, 800-622-3035 or 812-237-7887, 812-237-3022 (TTY). The cost is $25.00 for the video, $10.00 for the booklet, or $30.00 for both.

Usher Syndrome: Identification and Understanding
Poff, Lisa E. & Goehl, Karen S., Terre Haute, IN: Indiana Deafblind Services Project, 2000.
This set of materials contains a booklet, sample screening forms, and 2 videos. It provides basic information about Usher Syndrome, how to recognize the syndrome, and tests to help determine whether a person should be referred for medical testing. Available from the Indiana Deafblind Services Project, Blumberg Center, Indiana State University, School of Education, Rm 502, Terre Haute, IN 47809, 800-622-3035 or 812-237-7887, 812-237-3022 (TTY). The cost is $10.00 for the booklet or $60.00 for the set.

Conferences

Helen Keller National Center National Training Team
Professional Training Seminars 2002
Sands Point, New York

February 25 - March 1 Developing Strategies for Person-Centered Planning

April 8-12 Professional Development for Employment Training Specialists

May 29 - 31 Family Supports

September 9-13 Developing Strategies for Person-Centered Planning

October 21-25 Sensory Loss for the Elderly Population: Confident Living Program

November 18-22 Orientation and Mobility Techniques for Persons Who Are Deaf-Blind

Contact:
Doris Plansker
Phone: 516-944-8900 Ext. 233
TTY: 516-944-8637
E-mail: ntthknc@aol.com
Web: http://www.helenkeller.org/national

Deaf Way II
July 8-13, 2002
Gallaudet University
Washington, DC

Deaf Way II is an international conference and festival of the Deaf. Deaf, hard of hearing, and hearing participants from around the world gather to present and discuss issues of language, history, culture, art, technology, and human rights.

Contact:
Gallaudet University Kellogg Conference Center
Phone: 202-651-6064
TTY: 202-651-6112
E-mail: info@deafway.org or db.team@deafway.org
Web: http://www.deafway.org

Interpreters and support service providers are needed to provide services for people who are deaf-blind at Deaf Way II. If interested, contact db.team@deafway.org.

6th National Australian Deafblind Conference: Touching the World
July 12-15, 2002
Sydney, New South Wales, Australia

Contact:
Deafblind Association (NSW), Inc.
PO Box 1295
Strathfield
NSW 2135
Phone: (02) 4957 2741
TTY: (02) 9334 3260
E-mail: DBConference@gpo.com.au
http://www.dbansw.au.com

SALUTE Announcement

Please join Deborah Chen, June Downing, and others at http://www.projectsalute.net for stimulating discussions on Successful Adaptations for Learning to Use Touch Effectively!

- ❑ I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- ❑ I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- ❑ I'm buried in interesting publications! Please remove my name from your mailing list.

Name: _____ Agency: _____

Street: _____ City: _____ State: ____ Zip: _____

E-mail _____ Comments _____

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Mark appropriate categories (3 max.)

- ❑ **Person or parent of person who is disabled**
- ❑ **Special education (*e.g.*, teacher, aide)**
- ❑ **Administration (*e.g.*, Dept. of Ed., project director)**
- ❑ **Service provider (*e.g.*, social worker, group home)**
- ❑ **Technical assistance provider**
- ❑ **Higher education teacher/researcher**
- ❑ **Regular education (non Spec.-Ed.)**
- ❑ **Therapist (*e.g.*, OT/PT/speech)**
- ❑ **Teacher trainer**
- ❑ **Government personnel**
- ❑ **Medical professional**
- ❑ **Other** _____

Please send my copy in:

- ❑ Grade 2 braille
- ❑ Large print
- ❑ Standard print
- ❑ ASCII (__ Disk __ E-mail)

Mail to: *Deaf-Blind Perspectives*
Teaching Research Division
345 N. Monmouth Ave. Monmouth, OR 97361
or call Randy Klumph (503) 838-8885, TTY (503) 838-8821,
Fax: (503) 838-8150, E-mail: dbp@wou.edu

All issues of Deaf-Blind Perspectives *are available on the Internet at* ***www.tr.wou.edu/tr/dbp***

1201

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Deaf-Blind Perspectives

Volume 9, Issue 3 Spring 2002

He Didn't Listen

"Why would you want to adopt him?" the neonatologist asked 8 years ago.
"He'll never be more than a vegetable," he stated.
But Alex didn't listen, and now he jumps and shouts and laughs and loves his family.
"Alex may not ever be able to leave the hospital," the doctor said 7 years ago.
But Alex didn't listen, and it's been 4 ½ years since he was hospitalized.
"Alex will never eat or drink again by mouth," the experts told us 6 years ago.
But Alex didn't listen, and today he's eating and drinking, his G-tube 3 years removed.
"He may never walk," the therapist said 5 years ago.
But Alex didn't listen, and today he walks, runs, skips, and hops.
"He's profoundly retarded, incapable of much learning," the psychologist said 4 years ago.
But Alex didn't listen, and today he is learning to read.
"Even if he is legally blind and won't keep his glasses on, why are you trying contacts?
He won't keep those in either," the vision specialist said 3 years ago.
But Alex didn't listen, and those contacts (that he leaves in) have opened up a new world of discovery.
"We'd like Alex to increase his expressive language vocabulary to ten words," his Mom stated at the I.E.P. meeting.
The teacher for the deaf and hard of hearing laughed! "He will never be able to do that," she stated 2 years ago.
But Alex didn't listen and today signs dozens of words and understands over two hundred.
"Maybe potty training is beyond him cognitively," the therapist said 1 year ago.
But Alex didn't listen, and today he rarely wets himself.
So what will Alex be told he can't do next? Whatever it is, I pray that he won't listen.
And I hope that I won't either.

Jack Kemper, Alex's Dad

Alex

We should all be so determined when the odds are stacked so high against us. Alex has touched and continues to touch a lot of lives. We believe he teaches us all a lot about the wonders of life, love, laughter, determination, and the need for patience. We can only hope that the people who are in his future are willing to learn along with him on his journey. *Jack and Linda Kemper*

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Grade One Braille for Students Who Are Deafblind

Dr. Linda Mamer

Communication development is one of the most important issues for individuals who are deafblind. Educational best practices focus on using a communication approach that allows for the inclusion of multiple communication methods that work for each unique student. Methods include environmental cues, touch cues, natural gestures, tactile cues, fingerspelling, sign language, object cues, picture cues, voice, print, and braille. The primary educational goal is to help children who are deafblind become interactive communicators. A variety of strategies that support communication should be considered.

Braille, however, is often not considered as a learning media for some individuals who are deafblind because of the complexities of the Grade Two Braille code, which may be difficult for some students to learn. Grade Two Braille makes use of many contractions that use braille symbols to represent more than one letter. Contractions can represent whole words (e.g., the use of the letter "b" for the word "but"), short form words (e.g., the letters "chn" for "children"), or partial words (e.g., "ing"). There are 189 contractions and many rules associated with their use.

Grade One Braille is much simpler. It uses braille symbols for letters of the alphabet, punctuation marks, and numbers. It may be easier for many people to learn, including students who are deafblind. Grade One is also sometimes referred to as Braille One or Alphabetic Braille. Grade Two Braille is also called Braille Two or Contracted Braille.

Advantages of Grade One Braille

At the International Conference on English Braille, Grade Two in Washington, D.C. in 1982, the need for use of a simplified form of braille was presented by Marjorie Troughton, who at that time was a braille teacher at the W. Ross Macdonald School, a school for students who are blind, visually impaired, or deafblind in Brantford, Ontario, Canada. In 1992, in her book, *One is Fun* (1992), Troughton further explained her support for the use of Grade One Braille. Her rationale was based on the findings of a number of researchers and included the following:

- Grade Two Braille interferes with language patterns.
- Speed of character recognition is directly related to a learner's mental ability.
- Contractions do not reinforce basic phonics skills or allow students in regular education classrooms to sound out and spell words at the same time as their peers.
- Motivation of the learner and level of difficulty of the task is an important component in the ability to learn braille.

Troughton noted that many individuals would benefit from the use of Grade One Braille, including those

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who are deafblind, are newly blind, are able to do some work with large print but also need braille, and those who have learning disabilities, limited intellectual ability, or limited tactual sensitivity. It also may be useful for someone just learning to read—a young child in primary school, an adult in a literacy program, or a person learning English as a second language.

Grade One Braille is easy for interveners, family members, teachers, and peers to learn. People involved in the life of a child who is deafblind need to learn many new things, including specific communication techniques such as sign language. Learning braille, especially Grade Two Braille, may seem overwhelming. People seem more willing to learn Grade One, especially if it is presented as merely representations of letters of the alphabet. The family, teachers, and peers can learn Grade One Braille at the same time that the child is learning it.

Individualizing Braille Instruction

The team working with a child who is deafblind must conduct a complete and ongoing assessment of appropriate learning media and determine communication methods to be addressed. Some children may begin with Grade One Braille and eventually move on to Grade Two. For others, the most successful strategy is to stay with Grade One. Beginning with Grade One does not mean that a child is incapable of using Grade Two and staying with Grade One does not mean that a child has failed. Teachers and other team members need to individualize braille instruction to meet the needs of each child. The important thing is to build a foundation for successful communication. Grade One Braille may be an appropriate goal for a child who is deafblind.

Although many students ultimately move on to Grade Two, this may not be the case for every student. Ongoing, regular assessment of the student will guide the team when making that decision. Teachers may consider continuing with Grade One if it best meets the needs of the individual child. This may be different from what they learned in their teacher preparation programs or different from their experiences with children who are blind. Typically, teachers of students who are visually impaired have learned strategies for teaching braille that involve moving quickly on to Grade Two, or at least introducing some of the contractions fairly quickly. For some children, however, learning and staying with Grade One Braille may lay the foundation for a child's future success.

The speed at which a child learns is an important factor to take into consideration. Children who are deafblind often take a long time to learn something. It is important that braille-learning criteria for students who have blindness as the primary disability are not the only criteria used for students who are deafblind.

Strategies That Enhance Braille Learning

Develop Fine Motor Skills

Tactile activities that help develop fine motor skills are critical. Children who are deafblind need to learn to use and trust their hands. Children may be seen as lacking ability when, in fact, they haven't had sufficient exposure and opportunity to use and develop their hands. When children are exposed to meaningful, functional fine motor activities and finger play, their ability to use their arms, hands, and fingers often increase.

Develop Fingerspelling

Braille seems to be learned more easily when a child has developed some formal language, particularly fingerspelling. When hearing sighted children learn to read, they are learning a new code (print) connected to a code they already know (speech). Braille, like print, is a code, not a language. Children learning braille need to be able to apply this new code to a previously learned code in order for it to make sense.

In my experience, Grade One Braille works most effectively when a child knows how to fingerspell. It enables the learner to make a one-to-one correspondence between a fingerspelled letter and a braille letter. When I've read stories about how Helen Keller learned to communicate, I have been struck by how many hours each day that Annie Sullivan spent fingerspelling to Helen. Yet fingerspelling is a part of the total communication package that is often neglected, or at least it is not given enough time and emphasis. Educators may feel that fingerspelling is not a viable mode of communication for many children who are deafblind. They may believe, for example, that it is not an option for children who have physical limitations of the hands or fingers, have insufficient vision to see the letter symbols clearly, are uncomfortable touching another person's hands, or do not have the necessary cognitive skill (it is presumed) to learn how to fingerspell. These considerations may be important and should be discussed by the educational team, but it is crucial that the determination of a child's abilities is based on a thorough evaluation rather than assumptions.

The use of braille, even as a labeling tool, can begin to change people's perceptions of a child's abilities, particularly cognitive abilities. When braille is introduced into the environment, parents, teachers, and others may begin to think that the child has a higher

cognitive level than they previously thought. Because braille is an academic tool, the child may then be viewed as a more formal learner. Another advantage of Grade One Braille is that spelling ability is likely to be reinforced and improved as the child learns both fingerspelling and braille.

Label Items in the Environment With Grade One Braille Signs

Labeling items in the environment with printed words is commonly done for young sighted children who are learning to read. It is not expected that children will immediately be able to read the words, but rather that they will eventually learn them. Because braille is the equivalent code for children who cannot see, braille labels should be used in the same way. The easiest places to use braille labels are on concrete objects that the child is already familiar with, such as a cup, chair, toothbrush, nametag, ball, or table. The child is being exposed to braille at this point but is not reading the individual letters. However, we should believe that they might eventually either read the individual letters or read a word as a single unit. Ultimately, the child needs to make a one-to-one correspondence between the label and the object, just as he does when making a connection between a fingerspelled letter and a braille letter.

Grade One Braille Materials

Grade One Braille materials are easy to produce. Labels and short phrases about a child's activities or that identify objects in the environment can be created using a Perkins Brailler or hand held labeler. When children who are deafblind first learn to read, they typically read books that are created especially for each child, usually with the child helping. These books include experience, trip, or memory books about things that the child has done. Braille words and sentences can be added to the pages of these books by embossing the braille sentences on self-adhesive braille paper. The sentences can then be cut out and stuck to the pages of a book. When the child is ready to read the books that the class is reading, this same method can be used to add the Grade One Braille to the pages of picture books and early reading books. More advanced reading materials can be created using braille printers and computer software programs that translate text into Grade One or Grade Two Braille. Some commercially produced Grade One Braille books are also available. The American Printing House for the Blind (800-223-1839; http://www.aph.org) and Seedlings (800-777-8552; http://www.seedlings.org) each carry a few Grade One Braille books.

Research Findings

Although the use of Grade One Braille by children who are deafblind has not been formally evaluated, it has been evaluated for children who are blind. Sally Mangold (2000) reported the results of a policy adopted in one area of Minnesota that required teaching Grade One Braille during the first year of school, followed by a gradual introduction of Grade Two contractions.

Teachers involved in the program found that students who used Grade One Braille during the first year had higher academic achievement scores in reading rates and accuracy and greater academic and social interaction and participation with sighted students.

The Minnesota program also uses Grade One Braille for children with multiple disabilities and begins teaching Grade Two once they have thoroughly mastered the alphabet and have begun to read. Teachers have found a reduction in letter-reversal reading errors when Grade One is used for a longer period of time.

Conclusion

Braille is a viable tool to add to the total communication approach for individuals who are deafblind, especially for students who already have the beginnings of a code such as sign language or fingerspelling. Grade One Braille is another tool to help students succeed.

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Special thanks to Karen Nagel, STAR program, W. Ross Macdonald School, Brantford, Ontario Canada.

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Assessment as a Creative Action

Georgia Hambrecht, Ph.D.

Karen Goehl, M.S.

The Indiana Deafblind Services Project devoted its 2001 Family Learning Weekend to an exploration of the arts and creative expression. The focus was on art as a creative outlet and means of communication for students who are deaf-blind. After an initial discussion about the importance of creativity, master artisans from VSA arts of Indiana spent the weekend providing families with hands-on experiences with pottery and drum construction, large canvas painting, papermaking, and weaving.

At the end of the weekend, a reflective writing activity that we devised was used to allow families the freedom to express their feelings about the weekend in a playful and unrestricted way. Typical assessment procedures that use satisfaction surveys or group debriefing about the strengths and limitations of an experience would not have reflected the creative focus of the weekend. The writing activity used word tickets, described by Susan Wooldridge (1997) in a book about writing poems as taped, cut-out, printed words on "admit one" tickets. These tickets are "small, often colorful and valuable, allowing entrance to a special place." Each parent or family team was given a random assortment of 10 to 12 word tickets to serve as their word pool. They were asked to reflect on the weekend by writing a paragraph that included any 8 of the word tickets in their pool. Each parent or family team had 10 minutes to complete the paragraph. Their reflections were then shared with the other families. Here is a sample reflection that used the words "milk", "snapshot", "adults", "wish", "Bang Bang!", "vivid", "design", "glimpse", and "sophisticated":

> We got time for the *adults* to gather without the kids around. Very nice! We got a *glimpse* into other lives affected by deafblindness. The cameras are a great idea. We will put the *snapshots* in the kids' idea books. We drank more *milk* this weekend than we ever have at home! I (Jane) discovered that *vivid* color can be as beautiful as a *sophisticated design*; sometimes more so. One *wish* would be to have a weekend with presenters to help us learn how to acquire/access the financial assistance that is available. How to get the "result," not the "run around." The weekend was *Bang Bang*! terrific, especially when you consider the drums! They were a huge hit!

Staff examined the paragraphs to evaluate the participants' satisfaction with the weekend activities. Positive, negative, or neutral statements and themes were identified.

Statement analysis (positive, negative, or neutral):

- We got time for the *adults* to gather without the kids around. Very nice! (Positive)
- We got a *glimpse* into other lives affected by deafblindness. (Neutral)
- The cameras are a great idea. We will put the *snapshots* in the kids' idea books. (Positive)
- We drank more *milk* this weekend than we ever have at home! (Negative)
- I (Jane) discovered that *vivid* color can be as beautiful as a *sophisticated design*; sometimes more so. (Positive)
- One *wish* would be to have a weekend with presenters to help us learn how to acquire/access the financial assistance that is available. How to get the "result," not the "run around." (Neutral)
- The weekend was *Bang Bang*! terrific, especially when you consider the drums! They were a huge hit! (Positive)

Themes noted:

- Adult learning
- Awareness of others with deafblindness
- Creative experiences/ideas from weekend
- Food/Accommodations
- Future
- Unique individual expression

The use of a nontraditional assessment procedure provided the staff with useful evaluation information needed to determine the value of the activity and participant satisfaction. Participants had the freedom to identify matters they wished to address rather than respond to issues presented by the staff. We will continue to use and examine this and other alternative assessment techniques in an effort to obtain a broad range of information for program evaluation. We urge others to move beyond comfortable current evaluation procedures and search for new and creative assessment actions. For additional information, contact Karen Goehl at 800-622-3035.

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Mentoring Pilot Project

AADB Mentoring Pilot Project

Ashley Benton, Project Coordinator
Jamie McNamara, Project Director

The American Association of the Deaf-Blind (AADB), a national organization of deaf-blind people, is currently working on a four-year mentoring pilot project that is funded, in part, by DB-LINK. The project is consistent with DB-LINK's ongoing work to provide deaf-blind children and young adults, their families, and professionals access to information—an essential key to effective decision-making and quality of life.

The purpose of the project is to train deaf-blind adults to be effective mentors to deaf-blind youth. Mentoring offers deaf-blind youth an opportunity to gain knowledge, skills, and perspectives that hearing-sighted youth might routinely get from listening to the radio, watching TV, or listening to dinner conversations. It is our belief that the best role models are deaf-blind adults, who can show they lead successful lives despite hearing and vision loss.

The project design has four components:

1. Two groups of 5 to 6 deaf-blind adults will be trained to be mentors.
2. Each of these trained mentors will then mentor a deaf-blind youth for a year.
3. After one year the mentors will receive additional training on how to train other deaf-blind adults to be mentors.
4. During the last year of the project, a handbook on mentoring deaf-blind youth will be developed and disseminated through DB-LINK.

This project requires collaboration between state deaf-blind projects or supporting agencies and state or local deaf-blind organizations. The collaborations involve working together to match deaf-blind youth and adults and sharing the expenses necessary to support the mentoring experience.

We are pleased to announce that the mentoring pilot project had a very successful start. Five deaf-blind adults from Illinois, Indiana, Ohio, Texas, and Virginia received training on effective mentoring practices, and they are now mentoring deaf-blind youth. This first group of mentors consists of highly motivated individuals representing a cross-section of the diverse deaf-blind community. It includes individuals with Usher Syndrome Type 1, Usher Syndrome Type 2, and optic atrophy. Their communication methods include tactile, close up, and distance signing and speech/ lipreading.

The mentor training took place in Columbus, Ohio, September 8-9, 2001. The Great Lakes Area Regional Center for Deaf-Blind Education (GLARCDBE) graciously allowed use of their spacious classroom. Terri Gilliam from the Ohio Mentoring Project and Maricar Marquez were the two main speakers. Terri presented the effective mentoring component and focused on such things as general mentoring concepts and listening techniques. Maricar, who is deaf-blind, presented another component on topics relevant to working with deaf-blind youth, such as self-determination and recreation. AADB President Harry Anderson gave a motivational speech, and Ashley Benton discussed the expectations of the project.

The format of the training included a presentation on the concept of mentoring, role-playing, interviewing, and small group discussions. The presenters did a wonderful job and were very informative. We hope to continue to use the same presenters as a resource throughout the project.

The mentor training was not all work. There were opportunities for socialization during breaks and in the evenings. We gave all who participated a surprise gift, T-shirts with an AADB Mentoring Pilot Project logo. On the last day of training everyone wore their T-shirts and smiles for lots of pictures.

Now each mentor is busy hooking up and building relationships with the deaf-blind youth whom they will mentor for a year. The mentors are required to be in contact with the youths at least once a week through e-mail or instant messaging and to meet them for a face-to-face activity once a month. Based on the monthly reports we have received, things are going really well. Monthly activities have included ice skating, cooking, attending a holiday party at a deaf-blind organization, and learning American Sign Language.

Next steps are for the same mentors to gather again for the second mentor-training workshop about how to teach other deaf-blind adults in their states to be mentors.

A second group of new mentors will be selected in 2003 for the same opportunity as the first lucky bunch. If you would like more information or materials to apply to be included in the second group or if you would like to order a T-shirt, contact:

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National Curriculum for Deaf-Blind Persons and Interpreters

Mark J. Myers

On behalf of Northwestern Connecticut Community College and the Rehabilitation Services Administration of the United States Department of Education, we are very pleased to announce the completion of *The National Curriculum for Training Interpreters Working with People Who Are Deaf-Blind.*

The curriculum is a collaborative effort created by experienced and knowledgeable professionals in the field of program services and interpreting education. The goal is to provide curricular materials that train individuals to better serve persons who are Deaf-Blind. The curriculum consists of nine in-service training modules and a four-credit college course. The printed curriculum is presented in regular print, large print, braille formats, and also on diskette in ASCII. There are five videotaped programs that complement the curriculum.

This curriculum addresses the beginning, intermediate, and advanced levels of training needed. It enhances participants' familiarity with the basics such as the various etiologies represented in the Deaf-Blind community, tactile communication, interpreting visual information, comfort with touch, and sighted guide techniques. Beyond the basics, training focuses on more complex skills, such as making linguistic modifications for tactile communication, clarifying the roles and responsibilities of interpreters and support service providers (SSPs), and highlighting cross-cultural relationships between the Deaf-Blind, Deaf, and hearing cultures.

Copies of *The National Curriculum for Training Interpreters Working with People Who Are Deaf-Blind,* published by DawnSignPress, have been shipped to more than 125 interpreter education programs in colleges and universities across the nation and to the National Clearinghouse of Rehabilitation Training Materials. For a list of all the interpreter education programs, contact DB-LINK (800-438-9376 or 800-854-7013 TTY). If you are interested in the curriculum or have questions, please feel free to contact one of your local interpreter education preparation programs or Project Director Mark J. Myers via e-mail at mmyers@nwcc.commnet.edu or by phone at 860-738-6382.

DB-LINK

We'll find the information to answer your questions.

Call us!

DB-LINK
The National Information Clearinghouse
On Children Who Are Deaf-Blind
Phone: 800-438-9376
TTY: 800-854-7013
E-mail: dblink@tr.wou.edu
Web: http://www.tr.wou.edu/dblink

NTAC

NTAC Updates

NTAC, The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, provides technical assistance to state deaf-blind projects, families, and agencies throughout the United States. The content of technical assistance is quite varied and is based on individual state needs. It has been an exciting first year for NTAC's new grant. This column describes some recent state and regional activities.

Area 1

NTAC is working with states in Area 1 on a number of technical assistance activities on topics such as training and system development for postsecondary transition, addressing multicultural issues in service provision, family support provider training, and the use of technology to deliver technical assistance and training programs. An ongoing collaborative effort with the Oregon Deafblind Project provides one example.

The Oregon Deafblind Project is developing an intervener training initiative. A task force is addressing the following issues: 1) development of an Individualized Education Program (IEP) decision-making process to consider interveners as a service option; 2) development of a training system that makes use of the time and expertise of the project's regional deafblind consulting teachers; and 3) development of a competency based curriculum for individuals who work one-to-one with students who are deaf-blind. Other issues that will be addressed include administrative support, classroom teacher participation and support, and parent awareness. Three model sites are being established to implement the intervener training system.

In addition, the Oregon Deafblind Project and the Oregon Commission for the Blind have developed and are currently field testing an informative and easy to use *Family Transition Notebook*, a practical guide for transition teams. It provides guidelines and timelines about how to use the IEP process to address transition issues.

Reported by Shawn Barnard

Area 2

Area 2, in the middle region of the United States, is busy with a number of new long range technical assistance plans. NTAC is collaborating with states in the region on plans that address a variety of topics including transition, paraprofessionals, communication, and Usher Syndrome. A regional meeting is scheduled for August 2002 in Chicago. The meeting will focus on two topics—dealing with personnel shortages and effective post-secondary transition services.

Reported by Jamie McNamara

Area 3

Technical assistance activities in Area 3, in the southeast, also address a variety of topics. The Mississippi project is focusing on the development of an intervener pilot program with assistance from Texas Deaf-Blind Project staff. In Florida, the state project is involved in a pilot study on employment. Three individuals in transition and their teams are receiving intensive technical assistance and support to find jobs in their communities. The goal is to influence policy development in order for youth with severe disabilities to find meaningful community employment. Several states are continuing ongoing activities. Georgia is providing person-centered planning training at various locations throughout the state. Arkansas is continuing comprehensive follow-up and personalized training to teams who previously received IEP training. And South Carolina is continuing a training program on transition practices. A regional meeting will be held in August 2002. The primary topic will be building collaborative relationships with vocational rehabilitation and other adult service systems.

Reported by Amy Parker

You are welcome to copy articles from *Deaf-Blind Perspectives*. Please provide the appropriate citations.

E-Mail Discussion Groups About Deaf-Blindness

The Internet is a wonderful means of communication for people with shared interests but who live far apart from each other. E-mail discussion groups (also called e-mail lists) are one Internet tool that give deaf-blind people, family members, and professionals opportunities to share ideas, support, and points of view about many issues related to deaf-blindness. The following is a list of some e-mail groups that are currently active. If you are aware of others, please let us know by contacting DB-LINK (800-438-9376 or 800-854-7013 TTY).

Groups That Focus on Deaf-Blindness as a General Topic

Deafblnd Mailing List. The purpose of this list is to share information, inquiries, ideas, and opinions on matters pertaining to deaf-blindness. The list is open to professionals, persons who are deaf-blind, and to their families and friends. To subscribe send the following in the body of an e-mail message: SUBSCRIBE DEAFBLND firstname lastname (note that "deafblnd" is the correct spelling). Send to listserv@tr.wou.edu. For assistance contact Randy Klumph (klumphr@wou.edu).

Deaf-Blind Education Mailing List (DBED-L). The purpose of this list is to share information, inquiries, ideas, and opinions about deaf-blind education. To subscribe send the following in the body of an e-mail message: SUBSCRIBE DBED-L firstname lastname. Send to listserv@tr.wou.edu. For assistance contact Randy Klumph (klumphr@wou.edu).

National Family Association for Deaf-Blind List. This list is for parents and families. To subscribe, send a blank e-mail to nfadb@mailservice.cpd.usu.edu making sure that the word "subscribe" is in the subject line.

DBTeens. This is a private list for teenagers and young adults who are deaf-blind to share information, questions, ideas, and opinions about deaf-blindness and other issues. Contact Randy Klumph (klumphr@wou.edu) for subscription information.

Great Plains Deafblind List (Great Plains DB). This list is a support group for deaf-blind people, families, and professionals in the Helen Keller National Center Region 7 Great Plains states (KS, MO, NE, and IA) to share common experiences and interests. Discussions should primarily relate to giving support to people experiencing or in some way connected to deaf-blindness. To subscribe, send a blank e-mail to: GreatPlainsDBList-subscribe@topica.com. Or subscribe online at http://www.topica.com/lists/GreatPlainsDBList.

Deaf-Blind Mailing List (Sordoceguera). This list is entirely in Spanish. It is for deaf-blind people and families, volunteers, professionals, and educators. To subscribe send the following in the body of an e-mail message: SUBSCRIBE sordoceguera firstname lastname. Send to listserv@listserv.rediris.es. For assistance contact Ricard Lopez (talking3@teleline.es).

Deafblind Women Chat List. This list aims to support women who live with the daily challenges of deaf-blindness. Issues discussed may include such things as fashion and relationships, but the most important purpose is support. To subscribe send a blank e-mail to: dbwomenchat-subscribe@yahoogroups.com. To access via the Web, go to http://groups.yahoo.com/group/dbwomenchat/. For assistance contact Michelle Stevens (msteven5@bigpond.net.au).

Groups That Focus on Specific Syndromes Associated With Deaf-Blindness

Usher's Syndrome Mailing List. A list for people with Usher Syndrome, their parents, friends, spouses, and service providers. To subscribe send the following in the body of an e-mail message: SUBSCRIBE USHERS firstname lastname. Send to listserv@tr.wou.edu. For assistance contact Randall Pope (Ushers-request@tr.wou.edu).

CHARGE List. The topic of this list is CHARGE Syndrome. To subscribe, contact Casey Fisher (charge@neti.saber.net) or Lisa Weir (gweir@nbnet.nb.ca).

Rubella Discussion List (HKNC_Rubella). This group is a vehicle for parents, consumers, and professionals to share information about any aspect of rubella and to provide support to those living or working with someone who has congenital rubella syndrome. To subscribe contact Nancy O'Donnell (HKRegistry@aol.com).

Retinal Degeneration Discussion List (RPLIST). A forum for discussion, questions, and opinions related to retinal degeneration. To subscribe send a blank message to: rplist-subscribe-request@maelstrom.stjohns.edu. To access via the Web, go to http://www.dixonvision.com/rplist.

Refsum's Disease Mailing List. Refsum's Disease is a genetic disorder characterized by retinitis pigmentosa, anosmia, peripheral neuropathy, hearing loss, and less commonly, congenital abnormalities. To subscribe, send a blank email to: refsums_discussion-subscribe@yahoogroups.com. For assistance contact: refsums_discussion-owner@yahoogroups.com.

The following is an abridged version of an article that originally appeared in The Deaf-Blind American, 41(1), 2002. Reprinted here with permission. —Ed.

Birth of The World Federation of the Deafblind

Jeffrey Bohrman
Jamie McNamara

Did you know we, the deaf-blind, never had our own world deaf-blind organization until October 12, 2001? The deaf have their World Federation of the Deaf (WFD), and the blind have their World Blind Union (WBU). It was a proud moment in deaf-blind history to witness the birth of The World Federation of the Deafblind in Auckland, New Zealand among more than 300 participants: 114 deaf-blind and 204 supporters, from 46 countries. The meeting followed the 7th Helen Keller World Conference. The countries with the most participants were Sweden, which sent 91 people overseas and New Zealand, being the host, had 62 people. USA participants included 5 deaf-blind and 10 interpreters/SSPs. It was truly inspiring to meet deaf-blind people from all over the world who came together to add their voices to "Yes, we need WFDb!"

The founding general assembly of WFDb began on Thursday, October 11, 2001 with discussion of the draft charter constitution. This took up a bit of time because of language barriers in translations and different strong opinions from various countries. It was fascinating to watch all the translations of different languages (Japanese, Spanish, English, etc.) and the communication modes used (different sign languages, finger braille, fingerspelling, speech, etc.) for deaf-blind participants as well as the kinds of governments people came from (democracy, socialism) and their personal backgrounds (education level, employment, kind of deaf-blindness, etc.). Anyone can get an idea how unique it was to have this first general assembly!

There were nominations made for representatives from each region: North America, South America, Europe, Africa, Asia, and the South Pacific. Also there were nominations for other committees. With the exception of the charter constitution, only one delegate representing one country voted by secret ballot for the officers, regional representatives, and committee members. Jeffrey Bohrman was the delegate representing the United States and the American Association of the Deaf-Blind (AADB).

Election results for the following officers were announced: President, Stig Ohlson of Sweden; Vice President, Daniel Alvarez Reyes of Spain; Secretary General, Lex Grandia of Denmark; and Treasurer, Jeffrey S. Bohrman of the USA. Other election winners for regional representatives were also announced. Our North America regional representative is Craig MacLean of Canada.

The general assembly approved the following resolution for WFDb: "In line with all United Nations conventions on human rights, we, representatives of deafblind people of the world, united in Auckland at the Founding General Assembly of The World Federation of the Deafblind on October 12, 2001 urge all governments:

- To recognize deafblindness as a unique disability.
- To recognize all persons with deafblindness as persons with the right to full participation in all areas of society including education, information, communication, employment and political life.

To ensure the quality of life and full participation of all persons with deafblindness, we urge all governments to provide the necessary services including special education, guide services, interpreter services, accessible information, accessible communication and accessibility in the entire environment."

For more information contact wfdb@wfdb.org.

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Meeting Helen Keller

. . . a miscellany of first encounters

Compiled by Dana Cook

Martha Graham, dancer and teacher

Perceiving the dance

It was through Katharine [Cornell] that I met Helen Keller, who could not speak, see, or hear. Her speech was difficult to understand for those who did not know her. She was granted the ability to perceive life through her own unique awareness. She was a great lady, and very funny, too. She was, perhaps, the most gallant woman I have ever known.

Helen used to come to my school at 66 Fifth Avenue. She felt as if she was watching the dancing. What she was focusing on were the feet on the floor and the direction of the voices. She could not see the dance but was able to allow its vibrations to leave the floor and enter her body. She said to me once, in that funny voice of hers, "Martha, what is jumping? I don't understand." (New York, late 1930s)

From *Blood Memory: An Autobiography*, by Martha Graham (Doubleday, 1991).

Julian Huxley, scientist

How I 'felt'

. . . the dropping of the first atomic bomb on Hiroshima. . . deeply jolted our moral conscience, and when, shortly afterwards, I was invited to an enormous meeting at Madison Square Garden in New York, to speak on the future of this terrifying weapon, I accepted at once.

Behind the scenes I met other participants. . .and also that phenomenal creature, Helen Keller, who was struck with complete blindness and deafness at a few years of age. She had been brought out of this total immurement by a gifted woman who enabled her to communicate by spelling out sign language on her hand—and even taught her to speak, though the complete deafness to the sound of her voice made her utterance harsh and difficult to understand. Helen Keller was a very intelligent woman, with indomitable courage; she had won a college degree, and traveled all over the world in unending efforts to improve the condition of people deprived as she was.

She still relied largely on touch: when she asked if she might stroke my face I felt slightly embarrassed, but was delighted when she said: "I am so glad to know you, you feel just as I thought you would!" (New York, 1945)

From *Memories: Vol. I*, by Julian Huxley (George Allen and Unwin, 1970).

William L. Shirer, journalist

'Listened' to my broadcasts

Instantly I found Helen Keller beautiful and gracious, and before I realized it we were deep and passionately in a conversation. . . .

I was so carried away by her personality and wonderfully quick mind that I did not recall until later just how it was we conversed. As I remember it, I could not understand very well Miss Keller's words. They were spoken in a well-modulated voice (which of course she could not hear), but the words were blurred. So Miss Thomson repeated them. Sometimes when I spoke, Miss Thomson tapped out my words on the hands of Miss Keller. At other times, when our talk became animated, as it often did with such an eager and passionate woman, Miss Keller would put her fingers to my lips and lip-read.

To my surprise, she said she had been an "avid listener" to my broadcasts from Berlin (and to those of Ed Murrow from London), and she wanted to know, she said, how I had managed to survive the long years in Nazi Germany. She of course had not actually heard our broadcasts, but Polly Thomson had communicated them to her by what they called the "manual alphabet"—the tapping out of the words on her hand. (New York, 1947)

From *A Native's Return 1945-1988: A Memoir of a Life and Times*, by William L. Shirer (Little , Brown, 1990).

Yousof Karsh, portrait photographer

Inspired hope for humanity

When I met Miss Keller, we shook hands, and then, ever so lightly, she laid her fingers on my face, that she might photograph it in her mind, as I was studying her face through my eyes. Then, as we talked, her companion, Polly Thomson, translated my words by touch into the palm of Miss Keller's hand. I knew that my ideal picture would have to include not only that luminous, serene, yet vivid face, but those sensitive hands, together with the devoted concentration of her companion. To keep all these elements in the right proportion would be a challenge. I felt I must try, too, to transmit something even beyond this—the importance of her tremendous victory for humanity. Only a very insensitive person could leave Helen Keller's presence without feeling hope for humanity and faith in the Infinite. (New York, late 1940s)

From *In Search of Greatness*, by Yousof Karsh (University of Toronto Press, 1962).

Patty Duke, child star actor

Jolly grandma

Easily the most memorable visit to result from *The Miracle Worker*. . .was my meeting with Helen Keller. . .

When I first saw Helen walking down the stairs, she looked almost regal. She was wearing a blue dress, pearls, and what I found out were her favorite red shoes. She was close to eighty years old by then, but she carried herself very straight. She had alabaster skin, very thin white hair, almost like an angel's hair, and was very buxom with small hips and great-looking legs. And a terrific smile. And she was so jolly, like a jolly grandma. I'd expected serious or sweet, but got jolly. Not someone who was so much fun. Not someone who loved to laugh, and about everything, even the fact that we'd come before she'd had a chance to take her bras—rather large bras, I might add—in off the laundry line.

Helen hugged me and I hugged her and she told me that she'd heard from some friends how wonderful I was as her. Occasionally she would spell to me, just to be gracious and indulge me because I wanted her to, but mostly she would talk out loud. Her voice was very hard to understand, like a computer talking; she said she'd never been happy with the way it sounded. To understand me, she would put her thumb on my lips and her fingers on different vibration points. She didn't miss a thing. (Aachen Ridge, Conn., 1960).

From *Call Me Anna: The Autobiography of Patty Duke*, by Patty Duke with Kenneth Turan (Bantam, 1987).

For Your Library

Calendars for Students with Multiple Impairments Including Deafblindness

Blaha, R. Texas School for the Blind and Visually Impaired, 2001.

This resource guide about the use and development of calendars describes the benefits of calendar systems, provides information about calendar programming, and suggests ways for staff and families to help students expand their skills. Available from Texas School for the Blind and Visually Impaired, Business Office, 1100 West 45th Street, Austin, Texas 78756-3494. Phone: 512-206-9183. Web: http://www.tsbvi.edu. Cost: $30.00.

Communication Fact Sheets for Parents

McNulty, K. (Ed.). Monmouth, OR: National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC), 2002.

This booklet of fact sheets about communication (available later this summer) will cover a wide variety of topics including communication development, different communication methods, and assistive technology. For ordering information contact NTAC or check the NTAC web site after July 1st. Address: NTAC, Teaching Research, 345 N. Monmouth, Ave., Monmouth, OR 97361. Phone: 503-838-8808. TTY: 503-838-9623. E-mail: ntac@wou.edu. Web: http://www.tr.wou.edu/ntac.

Ethics in Deaf Education

Beattie, Rod G. (Ed.). San Diego: Academic Press, 2001.

This book is about ethics concerning education and deaf children and their families. Topics include ethics of assessment, educational placement, curriculum considerations, and personnel preparation. Available through bookstores. Cost: $69.95.

Orchid of the Bayou: A Deaf Woman Faces Blindness.

Carroll, C. & Fischer, C. H. Gallaudet University Press, 2001.

This is the story of Catherine (Kitty) Fischer who discovered as an adult that she had Usher Syndrome. The book addresses her upbringing and Louisiana Cajun heritage, early adult life, and how she coped with the diagnosis of Usher syndrome. Available through bookstores or from Gallaudet University Press. Phone: 800-621-2736. TTY: 888-630-9347.
Web: http://gupress.gallaudet.edu. Cost: $24.95.

The Teen Scene

Dell, S. J., LaPlante, T., Seamans-Terzian, S., & Cox T. L. Rhode Island Services to Children with Dual Sensory Impairments, 2001.

A comprehensive list of items and devices that might be enjoyable and stimulating for teenagers with disabilities, including vision and hearing loss. Available from Sherlock Center, Rhode Island College, 600 Mount Pleasant Ave., Providence, RI 02908. Phone: 401-568-8072. TTY: 401-456-8773. Cost: $5.00. The document is also available in alternative formats and on the web at http://www.ric.edu/uap/publications/teen.pdf.

Understanding Deafblindness: Issues, Perspectives, and Strategies.

Alsop, L. (Ed.). North Logan, UT: Hope Publishing, Inc., 2002.

A comprehensive 2-volume curriculum for parents, interveners, and service providers working with children and young adults who are deafblind. All aspects of deafblind programming are covered such as communication, concept development, vision, hearing, touch, sensory integration, intervention, family issues, physical education, additional disabilities, orientation and mobility, community support, and evaluation. Individual chapters were written by professionals with expertise in their respective subject areas. Available from Hope Publishing, Inc., 1856 North 1200 East, North Logan, UT 84321. Phone: 435-752-9533. E-mail: hope@hopepubl.com.
Web: http://www.hopepubl.com. Cost: $160.00

Early Hearing Screening and Intervention Web Sites

Early Hearing Detection and Intervention (EHDI) Program
http://www.cdc.gov/ncbddd/ehdi

This site describes the Centers for Disease Control EHDI Program. The program promotes early detection of hearing loss, tracking of infants and children who are deaf or hard of hearing, and the initiation of effective intervention systems in order to ensure that all newborns have the opportunity to communicate from birth. EHDI programs are implemented at the state level with collaboration and support from federal, state, and private organizations. There are currently programs in about 15 states. The web site contains a wealth of information about screening, state data, and research projects. Information in Spanish is also available.

National Campaign for Hearing Health
http://www.hearinghealth.net

Part of the mission of the National Campaign for Hearing Health is to advocate for universal newborn hearing screening. A document listing screening practices in each state (*State Report Card*) as well as additional information about newborn hearing screening can be found at this site.

Conferences and Events

Colorado 2002 Summer Institute on Deafblindness
June 26-28, 2002

The title of this program, presented by Phil Schwiegert, is *Using a Tangible Symbol System with Children with Severe and Multiple Disabilities, Including Deafblindness*. Cost: $75.00 registration fee for out of state personnel, plus costs of lodging, evening meals, and transportation.

Contact:
Tanni Anthony
Colorado Department of Education
201 E. Colfax
Denver, CO 80203
Phone: 303-866-6681
E-mail: anthony_t@cde.state.co.us

Family Learning Weekend: "Treasures"
June 28-30, 2002
Harrisburg/Hershey, Pennsylvania

This event is for families in Pennsylvania who have a child who is deaf-blind or at risk for deafblindness. It is sponsored by Hand in Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth who are Deafblind (The Pennsylvania Deafblind Project).

Contact:
Nancy Lehr
Hand in Hand in Hand
Phone: 800-360-7282, ext. 3115 (PA only)
E-mail: nlehr@pattan.k12.pa.us

Strategies to Communicate, Learn, and Interact by Moving and Doing
July 31 - August 2, 2002
Pennsylvania State University at State College, Pennsylvania

This summer institute presented by Therese Rafalowski Welch and Carolyn Monaco will provide instruction on communication strategies including learning about and constructing at least one of the following: schedule systems, tangible object symbols, experience books, and low-tech applications.

Contact:
Juli Baumgarner
Hand in Hand in Hand (Pennsylvania Deafblind Project)
Phone: 724-443-7821, ext. 238
E-mail: jbaumgarner@pattan.k12.pa.us

Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) International Conference: AERLoom Weaving a Tapestry of Services
July 17-21, 2002
Toronto, Canada

This conference will include more than 100 hours of professional development opportunities, along with networking and socializing.

Contact:
AERBVI
PO Box 22397
Alexandria, VA 22304
Phone: 703-823-9690
Web: http://www.aerbvi.org

Visions 2002: Seeing the Light
August 22-24, 2002
Chicago, Illinois

Visions 2002 is the annual national conference of the Foundation Fighting Blindness. It will include current research reports, resources, coping sessions, and networking and social functions.

Contact:
The Foundation Fighting Blindness
11435 Cronhill Drive
Owings Mills, MD 21117-2220
Phone: 888-394-3937
TTY: 800-683-5551
E-mail: info@blindness.org
Web: http://www.blindness.org

Deaf-Blind Access of the South (DBAS) Camp
October 3-6, 2002
Winder, Georgia

The camp will be held at the Will-A-Way Group Camp, Fort Yargo State Park. Activities include workshops, games, horseback riding, fishing, boating, crafts, hiking, and much more. Space is limited to 50 campers plus 70 to 80 support service providers and volunteer staff. Cost: $80.00. Registration forms and pictures from the 2001 camp are available on the Web site.

Contact:
Phone: 770-388-9809
TTY: 770-823-7437
E-mail: deafblindaccess@aol.com
Web: http://www.hometown.aol.com/deafblindaccess/index.html

20th Annual Closing The Gap Conference
October 17-19, 2002
Bloomington, Minnesota

Topics will cover a broad spectrum of technology as it is applied to all disabilities and age groups in education, rehabilitation, vocation, and independent living. Participants include people with disabilities, special educators, rehabilitation professionals, administrators, service providers, personnel managers, government officials, and hardware/software developers.

Contact:
Closing The Gap, Inc.
PO Box 68
Henderson, MN 56044
Phone: 507-248-3294
E-mail: info@closingthegap.com
Web: http://www.closingthegap.com

Zero to Three National Training Institute
December 6-8, 2002
Washington, DC

The National Training Institute is a multidisciplinary conference designed for experienced professionals (practitioners, trainers, supervisors, and leaders) in the infant/family field.

Contact:
Zero to Three: National Center for Infants, Toddlers and Families
2000 M Street, NW, Suite 200
Washington, DC 20036
Phone: 202-638-1144
Web: http://www.zerotothree.org

International TASH Conference
December 11-14, 2002
Boston, Massachusetts

The theme of this year's conference is "Our Quest: Opportunity, Equality, Justice." There will be over 350 breakout sessions that include cutting-edge, practical information about changing images, attitudes, and systems to empower individuals with disabilities and their families.

Contact:
TASH
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
Phone: 410-828-8274
TTY: 410-828-1306
E-mail: info@tash.org
Web: http://www.tash.org/2002conference

American Association of the Deaf-Blind (AADB)
2003 Conference
July 12-18, 2003
San Diego, California

AADB is a national consumer advocacy organization that promotes better opportunities and services for deaf-blind people. The 2003 conference will be held at San Diego State University. The cost is estimated to be around $800.00.

Contact:
AADB
814 Thayer Ave, Suite 302
Silver Spring, MD 20910-4500
TTY: 310-588-6545
Fax: 310-588-8705
E-mail: aadb@erols.com

Announcements

New Project SALUTE Website

The new website of Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively), http://www.projectsalute.net, provides (a) a description of the project and procedures, (b) an annotated bibliography and related links, and (c) information sheets related to project activities. This latter section, called "What We've Learned," includes the following topics:

- Definitions
- Tactile strategies
- Cues
- Symbols
- Signs
- Early literacy
- Working with Spanish-speaking families

The website contains a discussion board for posting and answering questions. We invite family members and service providers of children who are deaf-blind to join our discussion on issues related to tactile strategies.

Helen Keller National Center Registry of Persons Who Are Deaf-Blind

Have you ever wondered how many deaf-blind people there are in the United States or what the most common causes of deaf-blindness are reported to be? Do you know what kind of jobs deaf-blind adults have? The Helen Keller National Center (HKNC) maintains a voluntary registry of deaf-blind people of all ages. The purpose of the registry is to collect basic

information about the population of deaf-blind people in the United States. This information is used as a census of the population, to identify the needs of those who are deaf-blind, as a planning tool for services, and for research purposes.

In order to have the most accurate information possible, we need your participation. If you would like to be included in the registry or know someone who may wish to be included, contact Nancy O'Donnell or check out the website listed below. All identifying information is confidential. Written consent of the individual or guardian is required before it will be shared outside of HKNC.

Nancy O'Donnell
Helen Keller National Center
111 Middle Neck Road
Phone: 516-944-8900, ext. 223
TTY: 516-944-8637
E-mail: HKRegistry@aol.com
Web: http://www.helenkeller.org/national/registry-shortform.htm

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American Printing House for the Blind Initiative

The American Printing House for the Blind would like to announce its federal initiative designed to expand the knowledge and use of APH products and services, and to invite those with an interest in deaf-blindness to participate.

The National Instructional Partnership was initiated in 2000 to provide training in the use of APH products and information regarding related curriculum areas and instructional skills helpful when using APH products. APH is sponsoring the development of partnerships with experts in the field of blindness and deaf-blindness to initiate state and regional training opportunities for parents, consumers, and personnel who serve children who are visually impaired or who are deaf-blind. APH is currently contacting and contracting with successful APH product users in various arenas and curriculum areas.

The goal at APH is to partner with individual states and regions to offer dynamic training opportunities. APH will be responsible for coordinating presenters, travel arrangements, product delivery, and materials. If your state is interested in partnering with APH in planning a training event related to blindness or deaf-blindness or for more information, contact Field Services Representative Sandi Baker at 800-223-1839, ext. 266, or e-mail her at sbaker@aph.org.

Jamie McNamara Named Executive Director of AADB

(Press release from AADB President Harry C. Anderson)

The American Association of the Deaf-Blind (AADB), a national consumer organization of, for, and by deaf-blind Americans, is pleased to announce the appointment of Jamie McNamara as Executive Director of AADB. This is the first time that AADB has ever had an Executive Director. In recent months, the AADB Home Office has gone through critical staff shortages, prompting the AADB Board of Directors to act in order to keep AADB viable. This emergency action resulted in the appointment of Ms. McNamara to oversee the Home Office.

Ms. McNamara, herself deaf-blind, has been an active member of the AADB Board of Directors since 1997. She has been involved with numerous projects to make AADB a strong organization where deaf-blind people have a national voice. Ms. McNamara is committed to taking AADB to higher levels and helping the organization grow when she starts the job on May 6th. Her priorities will be focused on membership outreach; connections with legislators, manufacturers, service providers and deaf- and blind-related organizations; 2003 conference planning; and fundraising.

AADB is thrilled to have a strong deaf-blind leader for the Home Office and a role model for deaf-blind people everywhere. It's a great day for the national deaf-blind community to have a skilled deaf-blind Executive Director at AADB! Please feel free to contact or visit the AADB Home Office to say hello, ask how you can help or be involved with AADB activities, or how we can assist you with any questions.

AADB
814 Thayer Avenue, Suite 302
Silver Spring, MD 20910
TTY: (301) 588-6545
Fax: (301) 588-8705
E-mail: aadb@erols.com

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Fax: (503) 838-8150, E-mail: dbp@wou.edu

All issues of Deaf-Blind Perspectives *are available on the Internet at* ***www.tr.wou.edu/tr/dbp*** 0502

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